Cancer care services in Greece: A Delphi approach to investigate the views of healthcare providers and users

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A submission presented in partial fulfilment of the requirements of the University of Glamorgan / Prifysgol Morgannwg for the degree of Doctor of Philosophy

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University of Glamorgan
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ABSTRACT

Cancer is emerging as a major problem globally and effective cancer care services are needed to lessen its burden on the community. In Greece, oncology health service provision is not located efficiently, resulting in only few patients receiving high quality care. Furthermore, shortages of health professionals and underdeveloped services such as primary care, home care and palliative care in the Greek NHS have aggravated the problem. The limited resources for healthcare have led to the absence of a national cancer registry, thus the extent of cancer incidence cannot be evaluated effectively. The dissatisfaction of the population regarding the Greek NHS is well established, despite the numerous reforms proposed by consecutive Greek governments. It remains that limited research exists in the area of oncology, especially on cancer services and cancer care.

The aim of this study was to identify the key areas of cancer care and services that needed to be developed or improved in Greece and their prioritisation within the Greek healthcare system. Once identified, these areas of improvement could be used in a policy making context for the provision of effective services to cancer patients and might provide areas for further research.

A new Delphi technique (Q-Delphi) was introduced as an extension of the classical Delphi and implemented in two settings to collect data from a sample of 30 healthcare providers and 30 healthcare users. This was to reduce the potential subjectivity that may be introduced by the researcher in generating themes as an essential part of a successful Delphi outcome. The Q-Delphi of healthcare providers consisted of three rounds while that of the healthcare users was based on two rounds.

The response rates for all rounds in both Q-Delphi studies were over 77%. The priorities for healthcare providers were focused on staff shortages, working conditions, pain management, home care, day units and communication. Healthcare users' highest priorities included the provision of and research on effective treatment, lessening the financial costs involved and the organisation of cancer services. Despite the separate Delphi studies, there were areas that both healthcare providers and users identified and prioritised. However, for the areas that both panels shared, there was a significant difference between their prioritisation.

The World Health Organisation (WHO) suggestions for controlling cancer were used to triangulate, explain and discuss the results from this study (WHO 2002). The areas identified by healthcare providers and users were within those recommended by WHO. Based on the priorities provided by the participants and the suggestions by WHO, the establishment of a national cancer registry, the employment of nurses in order to develop primary care, home care, day care and palliative care services, education in communication skills and redistribution of the bio-medical technology are recommended in order to reduce the burden of cancer in Greece.

More research is needed to validate the actual level of cancer services provided in Greece. In addition, Q-Delphi is suggested as a valid and objective research method.

For the benefit of Greek researchers, copies of documents used in conducting the research are also presented in Greek (Appendices 3 to 13 and 15).

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LIST OF CONFERENCE PRESENTATIONS AND ACHIEVEMENTS

1999 Novice Researcher Award, by the European Oncology Nursing Society, at the 10th European Cancer Conference (ECCO 10)

The title of the paper presented at that conference was: 'What constitutes good cancer care in Greece: Health professionals' views' and the abstract has been published in the *European Journal of Cancer*, vol 35, Supp 4, September 1999, Page S39

2001 'Health professionals' views on cancer care in Greece'. *Oncologiki Enimerosi*, vol 3, no2, April-June 2001 (in Greek)

2002 Award by the European Oncology Nursing Society and ROCHE pharmaceutical company

The award included funding for the Q-Delphi study of the healthcare users' views.

GLOSSARY - ABBREVIATIONS

ACCP	Advisory Committee on Cancer Prevention
ASR	An age-standardised rate (ASR) is a summary measure of a rate that a population would have if it had a standard age structure. Standardisation is necessary when comparing several populations that differ with respect to age, because age has such a powerful influence on the risk of cancer. The most frequently used standard populations are the World and the European standard populations. The calculated incidence or mortality rate is then called the World age standardised or European age standardised incidence or mortality rate. They are expressed as a rate per 100000.
BSE	Breast Self Examination
CBE	Clinical Breast Examination
CI	Confidence Interval is the range of values within which a population parameter is estimated to lie
Content analysis	A procedure for analysing written or verbal communications in a systematic and objective fashion, typically with the goal of quantitatively measuring variables
Content validity	The degree to which the items in an instrument adequately represent the universe of content
Concurrent validity	The degree to which scores on an instrument are correlated with some external criterion, measured at the same time
EU	European Union
HADS	Hospital Anxiety and Depression Scale
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
IARC	International Agency for Research in Cancer
GDP	Gross domestic product (GDP), is the market value of all goods and services produced in a year within a country's borders. It is the standard measure of the overall size of the economy.

Incidence	Occurrence of new cases of a disease in a defined population in a defined period of time.
Mortality	The whole sum or number of deaths in a given time or a given community; also the proportion of deaths to population, or to a specific number of the population.
Morbidity	Incidence of disease in a population, including both fatal and nonfatal cases
NHS	National Health System
NMC	Nursing and Midwifery Council
OECD	Organisation for Economic Co-operation and Development
Prevalence	Statistic that equals the total number of people in a population with a certain disease at a given time
RCN	Royal College of Nursing
Reliability	The degree of consistency or dependability with which an instrument measures the attribute it is designed to measure
TCRC	Tobacco Control Resource Centre
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

CHAPTER ONE

1. INTRODUCTION

Cancer is one of the most common diseases of modern times. It is anticipated that one in three people will get the disease and one in four will die from it (Department of Health 2000a). Its multiple sites, presentations, complications, and the complexity of its treatment present a major challenge to the healthcare system of any country. In addition, the consequences of the diagnosis of a malignant disease for the patient are far reaching and profound. In Greece, cancer services and cancer care have, to date, only attracted limited attention by researchers with the result that assumptions only can be made for these areas from research on general populations who have expressed dissatisfaction with the Greek National Health Services (Ferrera 1993, Komninou 2000).

Cancer not only affects the individual but also places a heavy burden on the community. Fortunately, in comparison to other European countries, Greece has low cancer incidence and mortality rates (Black *et al.* 1997, Bray *et al.* 2002). However, due to the lack of a national cancer registry, the epidemiological data available are only estimates based on other countries similar to Greece. Furthermore, cancer incidence has also been shown to increase with age (WHO 2001). As the ageing population is rapidly rising in Greece (WHO 1998a), it is expected that there will be an increasing demand for cancer services in the future.

Cancer care is provided in designated cancer hospitals, in many district general hospitals and in seven university hospitals situated in large cities in Greece. Primary care, which is seen as the focus of care in most countries, is not very well developed in Greece, thus standards of care vary for patients. Essential aspects of primary care such as cancer prevention are not effectively provided. Prevention programmes are mostly initiated by non-governmental parties, resulting in only few people benefiting. The ineffectiveness of prevention strategies within the healthcare sector is reflected in the increasing number of adult smokers in Greece (TCRC 2000).

Due to the lack of resources and the fact that healthcare was never a priority for consecutive Greek governments (Niakas 1993), secondary and tertiary cancer care are mostly offered in hospitals close to big cities resulting in a large number of rural patients having to travel long distances for treatment. However, an advantage of centralised services is that they offer more effective cancer care (Payen and Jarrett 2000). Furthermore, hospices do not exist and home care is limited (Kerskra and Hutten 1996, Fragoulidou and Zyga 1999). The lack of these services minimises the provision of palliative care. Palliative care is considered as an integral part of all cancer patients' care. It has been widely acknowledged that the principles of palliative care could apply across all conditions and in all settings and should be provided for every patient with cancer as soon as diagnosis has been confirmed (Department of Health 2000a).

Pain management and psychological support are essential elements of palliative care. According to international data (Hockley *et al.* 1988, Higginson and Hearn 1997, Mercadante *et al.* 2000), a large number of cancer patients suffer from pain even when palliative care is provided. In Greece, pain clinics exist in most hospitals and are run by anaesthetic departments. However, there are only limited studies on the incidence of pain for Greek cancer patients and limited studies which have evaluated the effectiveness of existing pain clinics (Mystakidou 1999). As a result, assumptions only can be made on the incidence of pain in Greece based on international data. The psycho-social problems among cancer patients and their carers are also well documented (Zabora *et al.* 2001). Despite the evidence suggesting that psychological interventions can improve cancer patients' quality of life (Sellick and Crooks 1999), health professionals fail to understand the extent of the problem and only few patients or carers receive any type of psychosocial support (Eriksson and Lauri 2000).

Communication between healthcare professionals and cancer patients and especially information giving regarding their cancer diagnosis forms another important issue in the area of cancer care. There is evidence that a large number of Greek cancer patients are not aware of their diagnosis and prognosis (Iconomou *et al.* 2002). Cancer continues to remain a taboo issue and is still associated with a high level of unnecessary suffering and death. Greek health professionals are not keen in breaking

bad news of the diagnosis to patients due to the existing culture and the lack of education on communication skills (Mystakidou *et al.* 1996). This may have considerable implications as a large number of cancer patients may not be able to make informed decisions about their treatment or offer their views on the development or improvement of cancer services since they are not aware of their diagnosis.

Cancer care provision has not been given a high profile on the political agenda in Greece as indicators such as cancer incidence and mortality rates are low. It should be noted that the philosophy of successive Greek governments regarding healthcare has been one of addressing problems as soon as they arise (Petridou *et al.* 1999). However, the dissatisfaction existing in the area of healthcare among healthcare providers and users (Komninou 2000), including cancer patients, has forced some issues onto the public agenda that require action by the Greek government. Decision makers usually provide policies that will shape the future improvement or development of services. The process of policy making is complicated and involves various participants (West and Scott 2000). However, decisions for the provision of health services in the Greek NHS are often taken centrally by committees consisting mainly of doctors and academics. So far, little attention has been given to the views of other healthcare professionals and healthcare users. Only recently has there been some research that has focused on users' views (Iconomou *et al.* 2001). However, there is no evidence to suggest that these views have been considered in any policy making.

It should be noted that the focus of this study was not to provide an in-depth review of the pathophysiology, treatment regimes of specific cancers or the economics and management of cancer services and hence, these issues are not discussed. Furthermore, it was not the intention to create a policy report, rather to identify the priorities in cancer care services for healthcare providers and users and provide them to decision makers to consider in future policy making.

The aim of this study was to determine and prioritise the areas of cancer care and cancer services that should be improved or developed in Greece. This was achieved through the following:

- A Delphi study to identify and prioritise the areas of cancer care and cancer services that need to be improved or developmed from a panel of healthcare providers;
- A Delphi study to identify and prioritise the same areas of concern from a panel of healthcare users;
- The use of a theoretical framework to triangulate and interpret the results obtained from the two Delphi studies.

From the above, a compromised list of priorities would be identified in the area of cancer care services development in Greece. These will be based on the WHO (2002) recommendations compared with the priorities highlighted by both healthcare users and providers.

In trying to establish the priorities in the areas of development and improvement of cancer care and cancer services, the views of a sample of healthcare providers and healthcare users were obtained. Thus, the opinions of two groups of experts were used ('experts' that is in the Delphi sense of the word). Such experts were healthcare providers involved in care giving and the users of services as experts by virtue of their experience. In exploring the views of healthcare providers and users for this study, a Delphi technique (described in Chapter three) was considered to be appropriate in determining and obtaining a consensus view from both groups about the priority of the improvements or the development needed.

As the classical Delphi technique was found to have elements of researcher subjectivity in the content analysis of the participants' responses, a new Delphi approach was developed as a more rigorous approach to overcome this problem. By using this new method, named Q-Delphi, the experts were asked to identify the areas of cancer care and cancer services that should be developed or improved. Once these were identified, an external panel of healthcare researchers undertook the content

analysis of the data to provide themes under which the participants' suggestions would be presented for prioritisation as a next stage. The final outcome would be a prioritised list of cancer care issues and cancer services that would serve as an input in the policy making context.

The World Health Organisation (2002) published a report which considered the burden of cancer in communities and the available resources for healthcare provision in different countries. The report suggests action to be taken in the areas of prevention, early detection, treatment and palliative care in order to control cancer incidence and improve the quality of life of cancer patients. Depending on the level of resources available, the proposed actions have been set at three levels of 'high', 'medium' and 'low' corresponding to the countries' level of income and resources available for healthcare.

For Greece, healthcare resources were considered to be compatible with those of the medium level scenario which was adopted as the 'ideal type' for Greece. The term 'ideal type' was taken by Weber's theory on bureaucracy (Weber 1905). The 'ideal type' scenario forms the conceptual framework with which the opinions and priorities identified by both groups of participants will be compared. The following diagram (Figure 1.1), shows the 'ideal type' cancer control programme for Greece as suggested in this study.

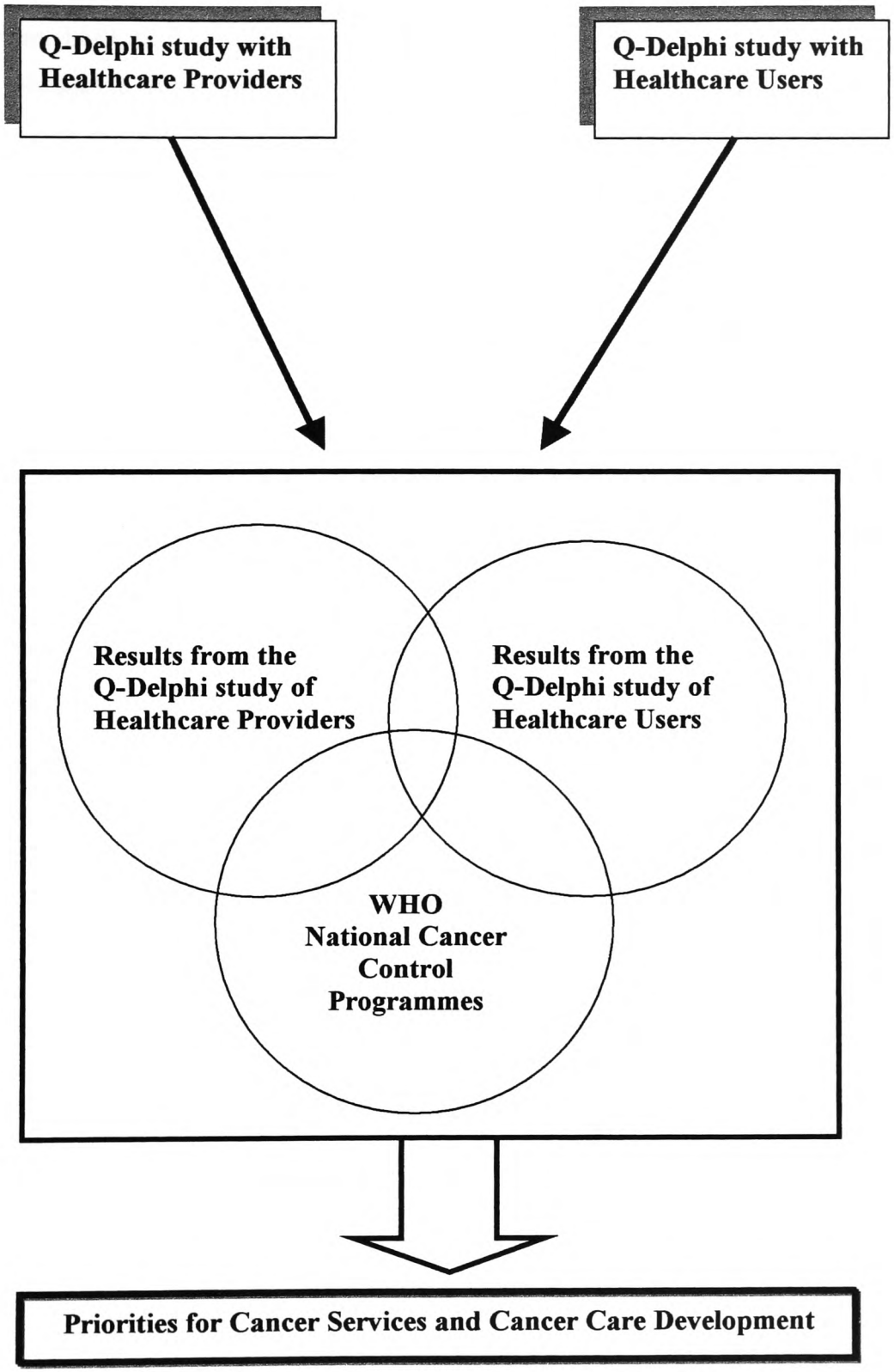


Figure 1.1 The 'ideal type' cancer control programme for Greece

With regards to the project's time frame, it has to be noted that it was undertaken on a part-time basis after enrolling on September 1996. Following a literature search and an investigation of the methods that could be used to establish priorities in the area of cancer care services in Greece, the use of Delphi technique was thought appropriate. After a pilot study, the research project started in 1998 with the healthcare providers using the classical Delphi technique. In 1999, a change in the supervision team occurred leading to a delay in the implementation of the healthcare providers' Delphi study. After completing both studies and at the initial stage of analysing the data and writing up of the thesis, due to supervision difficulties the project was further delayed, making the completion of the thesis almost impossible. In 2002, a complete change of the supervision team took place, including the appointment of a new director of studies. Since then, a complete revision of the research process took place. It led me to revise and generalise the classical Delphi approach which I called Q-Delphi. Following this, a new 'Methods' chapter was added to my work including the identification and selection of the WHO (2002) guidelines as a yardstick to compare the results of the healthcare providers' and users' priorities. The new methods chapter resulted in a re-analysis of the data, triangulation of the findings and conclusions. The following table (Table 1.1) shows the time frame of the whole project:

	January	February	March	April	May	June	July	August	September	October	November	December
1996										SEARCHING THE LITERATURE		
1997	SEARCHING THE LITERATURE							DECIDING ON THE METHOD TO BE USED				
1998			PILOT STUDY		CLASSICAL DELPHI STUDY OF HEALTHCARE PROVIDERS							
1999		CHANGE OF SUPERVISION TEAM / CLASSICAL DELPHI STUDY OF HEALTHCARE USERS										
2000	ANALYSIS OF DATA											
2001	WRITING UP OF THE THESIS / ADDITIONAL SEARCH OF THE LITERATURE											
2002	CHANGE OF SUPERVISION TEAM / RE-EXAMINING THE RESEARCH PROBLEM / INTRODUCING Q-DELPHI RE-DESIGNING THE METHODS INCLUDING THE USE OF WHO GUIDELINES AS A YARDSTICK EXTENSION OF THE DELPHI APPROACH / ADDITIONAL SEARCH OF THE LITERATURE											
2003	RE-ANALYSIS OF DATA USING Q-DELPHI AND THE USE OF WHO GUIDELINES UPDATING THE LITERATURE										SUBMISSION	

Table 1.1 Time frame of the thesis

1.1 Overview of the thesis

The thesis consists of seven chapters. Chapter one, the introduction, deals with the aims of the study and a justification for the methodological approach adopted. The next chapter is a review of the literature. This review is divided into four sections. The first briefly describes the Greek health system with some insight provided into the environment where the study took place. Demographic data on cancer incidence and mortality in Greece are also provided. The second section deals with the provision of cancer care services in Greece in the area of primary, secondary and tertiary care. The provision of palliative care is also considered. The third section provides information regarding the satisfaction among healthcare providers and users with the Greek NHS. The final section deals with the issue of policy making and the involvement of healthcare users in the area of cancer care services development.

Chapter three deals with the methodological considerations in conducting two Delphi studies by obtaining the views of healthcare providers and healthcare users on cancer care and cancer service priorities. Other methods which were considered in conducting this study are also discussed. Chapter four describes the conceptual framework for the study and the model proposed by WHO in establishing national cancer programmes for cancer control. This model, and especially the medium level scenario proposed by WHO, was considered to be the 'ideal type' scenario for Greece.

The results from both Delphi studies are presented in Chapter five. This chapter is divided into three sections presenting the results for the panel of healthcare providers, the panel of healthcare users and the results comparing data from both groups. In Chapter six, the results are discussed under the conceptual framework developed by the researcher based on the WHO recommendations on controlling cancer for this study. The results are also considered under the context of policy making. A critical discussion of the limitations and the strengths of the study follow this. Finally, Chapter seven presents the conclusions to the study followed by the contribution of the current study to new knowledge. Recommendations for practice, for future research and researchers are also made.

CHAPTER TWO

2. A CRITICAL REVIEW OF THE LITERATURE

The review of the literature on cancer care provision and user involvement in the area of cancer care was undertaken utilising a database search which employed CancerLit (1991-2002), Medline (1966-2004), CINAHL (cumulative index to nursing and allied health literature) (1982-2004), Nursing Collection (1995-2004), Embase (1980-1999) and Healthstar (1990-1996). Searches were also carried out from several online internet journals, such as the British Medical Journal and the Journal of Advanced Nursing over the past 15 years. Reference lists from journal articles were scanned for additional relevant information. Hand searches were also performed and grey literature was used when appropriate such as government reports and official documents that were not published at the time the literature review was written.

The majority of the literature had been published in America, Australia and Europe, mainly in the United Kingdom. The main keyword for the literature search was 'cancer' followed by any possible combination of words such as services, priorities, communication and Greece. The full range of keywords used in the literature search is shown in figure 2.1.

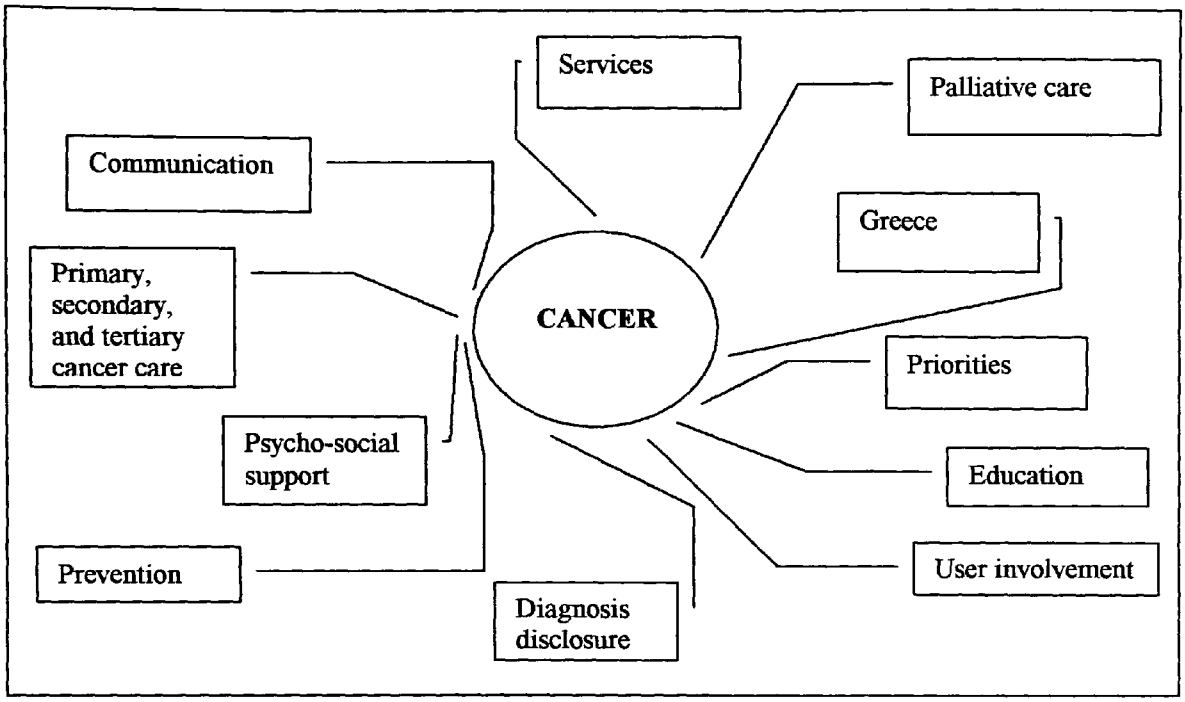


Figure 2.1 The main terms used for the searching of the literature

The review of the literature is one of the most important undertakings of any research project. The review process helps researchers to establish what is known and what is not known about their subject area. Ultimately, the aim is to summarise the literature so that the current state of knowledge is revealed, and to demonstrate a relationship between what the researcher hopes to achieve and the previous work. However, in order to do this, thoughtful consideration must be given to the cumulative evidence with both the strengths and weaknesses identified (LoBiondo-Wood and Haber 2002).

For the purpose of this study, it was felt important to establish what is generally accepted as effective provision of cancer care services and how these services may be developed or improved. Much of the literature used in this study to describe effective practices and policy making in the area of cancer care comes from the United Kingdom, as the Greek literature in cancer care and policy making is very limited. However, the Greek National Health System, established in the early 1980s, is modelled on the British National Health System (Petridou *et al.* 1999). Despite the deficits in primary healthcare services and other minor differences, there are still considerable similarities. For this reason, studies from United Kingdom are

frequently cited in this review. In the area of cancer care, WHO (2001) also cites UK as an example where cancer services are effectively organised.

In an effort to search the Greek literature on cancer care, the only available source was used which is the Hellenic National Documentation Centre (EKT) which belongs to the Hellenic National Institution of Research. The Ippokrates search engine was used, which is the Greek Medline equivalent (Tsalapatani 2001). Using the keyword 'cancer' resulted in 318 articles in Greek language and 299 PhD theses. A hand search on the available Greek medical and nursing journals between 1990 and 2004 revealed more review articles but few research studies. However, the search on the electronic databases of Medline, Cinahl, CancerLit and Healthstar revealed over 200 publications on oncology by Greek authors. An effort was made to locate all the available and relevant Greek literature on cancer, either in Greek or in English language, and they have been critically discussed.

2.1 CANCER CARE IN GREECE

2.1.1 Introduction and Historical Background

Greece, or the Hellenic Republic as it is officially called, is a relatively small country with a total land area of 131,957 km^2. It is part of the Balkan Peninsula extending down into the Mediterranean Sea. Greece's topography is highly diverse. The land is mainly mountainous with a few plains. The numerous islands in the Aegean and Ionian Seas occupy about one-fifth of its territory. The temperature is moderate during the winter in the south and colder in the north, but it is high throughout the entire country during the summer. Sunny days average 300 per year in the southern islands, 250 in Athens and 230 in northern and western Greece.

According to the latest national census, the population in 2001 was 10,623,000 (www.statistics.gr). The capital is Athens, with a population of about 3,400,000. The majority of Greek people belong to the Greek Orthodox Church, while there are small groups of Moslems, Jews, Roman Catholics and Protestants. In recent years there has been a large influx of illegal immigrants, mainly from Albania, and to a lesser extent from Poland, Russia and other eastern European countries. Agriculture in Greece employs about 22% of the workforce and accounts for about 15% of the gross domestic product (GDP) while industry employs about 25% of the workforce and accounts for nearly 28% of the GDP (EUROSTAT 1994). Tourism and shipping are major sources of income (WHO 1996).

Greece is a democracy whose new written constitution was enacted in 1975. The Chamber of Deputies (300 members) is elected every four years. The President, elected by the Chamber of Deputies, holds a largely ceremonial position. The largest political parties in the 1980s and 1990s are the Panhellenic Socialist Movement (PASOK) and New Democracy (about 80% of the vote in elections of recent years). Education is free and compulsory for nine years. The literacy rate is 94%. Life expectancy in Greece is among the highest in Europe and in the world. Major causes of death are attributable to heart disease, malignant neoplasms, cerebrovascular diseases, accidents and diseases of the respiratory system (WHO 1998a).

2.1.2 The Greek Health System

In Greece, the concept of healthcare was encountered very early in historic times. Aesculapeus was worshiped as the God of Medicine and his daughter, Hygea, was worshiped as Goddess of Health in the fifth century BC. During the last century, considerable efforts have been made to establish a National Health Service and decentralise health services.

It was only when the Socialist Party (PASOK) came to power in 1981 that the prevailing conditions resulted in a radical change of the Greek healthcare system. In 1983, the government passed legislation introducing a National Health Service (NHS). The following principles were embodied in the reform:

- Equity in the delivery and financing of healthcare services;
- Primary healthcare development;
- A new public-private mix in provision;
- Decentralisation in the planning process, improvements in management and community participation (WHO 1996).

However, the 1983 legislation was only partially implemented. The most crucial step taken was the establishment of rural health centres and the establishment of three large university hospitals. Furthermore, health centres were not established in urban areas and a referral system was never implemented in the country as well as decentralisation in the planning process. As a result, the problems of the healthcare system continue to persist and this has led to numerous efforts to initiate radical reforms in the Greek NHS. In an attempt to deal with all the major shortcomings of the system that the 1983 reform failed to resolve, a major reform proposal was put forward in 1996 and, up to the present, other less radical reforms have been proposed.

2.1.2.1 Organisation of the Greek NHS

The Ministry of Health and Welfare is the leading institution in developing and financing health policies. The Ministry is responsible for the financing and the provision of the National Health Service as well as health and social services for the

poor, the elderly, and the disabled. Despite the introduction of committees, such as the Central Health Council and Regional Health Councils with planning and administrative responsibilities, the Greek health system remains highly centralised. Virtually every aspect of healthcare financing and provision is subject to control by the Ministry of Health (Petridou *et al.* 1999).

The structure of the Greek NHS is based on the regional and district division of the country (there are 13 regions and 52 prefectures or districts). Figure 2.2 shows the regional division of Greece. The average population size is 200,000 for the districts (excluding Athens and Thessaloniki) and 800,000 for the regions (excluding Athens). Each of the prefectures has at least one district hospital while each region should have one regional hospital which, in most cases should be a university teaching hospital. However, at present, only seven of the 13 regions have large university teaching hospitals two of which are in Athens and Thessaloniki, and the remaining regions are served by the nearest regional hospital in the case of tertiary care (WHO 1998b).

Although it was not the intention of this chapter to provide a detailed overview on the Greek healthcare system, it was considered important to understand the environment in which cancer care is offered and where this study took place.

Figure 2.2 The regional division of Greece

2.1.3 Cancer Care and Historical Background

The term cancer is used generically for more than 100 different diseases including malignant tumours of different sites. Common to all forms of the disease is the failure of the mechanisms that regulate normal cell growth, proliferation and cell death (WHO 2002). Cancer is a disease with a profound effect on every aspect of life. Despite improvements in cure rates, many uncertainties persist concerning the nature and causes of cancer and methods of prevention and cure. For many years cancer is not only considered as a cellular dysfunction, but an historic event, a social, economic and ethical dilemma (Cassileth 1979).

The disease of cancer was first recorded on Egyptian papyri written in the seventeenth century BC. In Ancient Greece, Hippocrates sought to unravel the mysteries of this disease ("carcinos" in Greek, meaning crab, whose Latin term gave the English name to the disease), and attempted to treat it. Hippocrates refers to superficial and deep cancer and considered cancer as a disease of old age (Dontas 1995a). Later, the physician Leonides described breast cancer and his contemporary Archigenes, described cancer of the uterus (Denton 1988). After these descriptions and until the Renaissance, little new knowledge regarding the disease of cancer is evident. During the centuries, a belief such as that cancer is contagious, created a leprosy like aura around cancer in the public mind (Cassileth 1979). In 1740, Canon Godenot in Reims, France opened the first cancer hospital and it was only after the eighteenth century that progress was made in the treatment of cancer (Denton 1988).

In Modern Greece the first oncology hospital, 'Agios Savvas', was founded in 1935 by a Christian social union and it was the 14th anti-cancer institute in the whole world (Dontas 1995b). In 1934, there were 30,000 to 40,000 cancer patients in Greece of which 7,000 died of the disease (Kordiolis 1995).

2.1.4 Cancer Figures and Facts

Cancer incidences appear to be rising and it has been estimated that if current trends persist, by the year 2050, 1 in 2 people in Europe will develop cancer during their lifetime (Einhorn 1989). Furthermore, Eaton (2003), examining the WHO reports,

suggested that cancer rates would be doubled by 2020. It is estimated that there were 2.6 million new cases of cancer in Europe in 1995, representing over one-quarter of the world burden of cancer (Bray *et al* 2002). According to the International Association of Research in Cancer (1996) the main sites of incidence for the European population are the lung for men (21%) and the breast for women (28%).

There appears to be a considerable difference between the incidence and mortality rates in Greece and the rest of the European countries. Figure 2.3 shows the age-standardised cancer incidence rates for Greece and Europe and figure 2.4 shows the age-standardised cancer mortality rates for Greece and Europe (Bray *et al.* 2002).

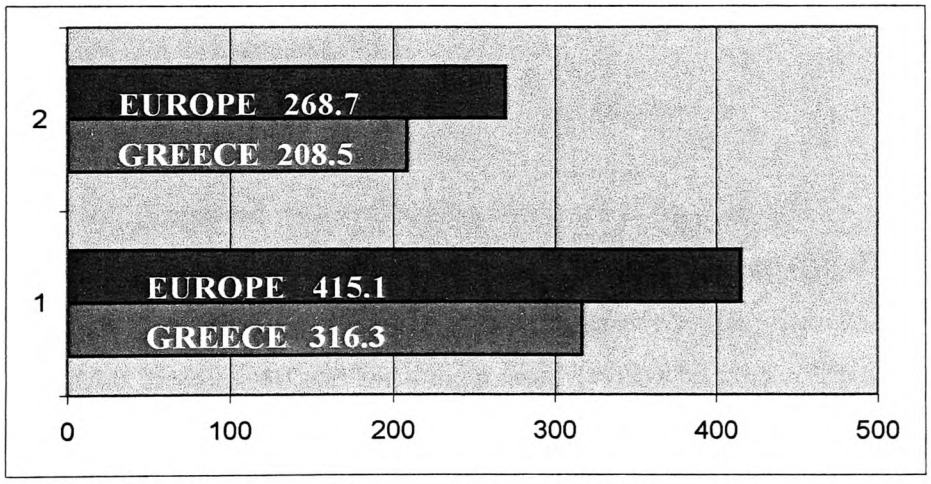


Figure 2.3 Age-standardised cancer incidence rates for Greece and Europe (1995)

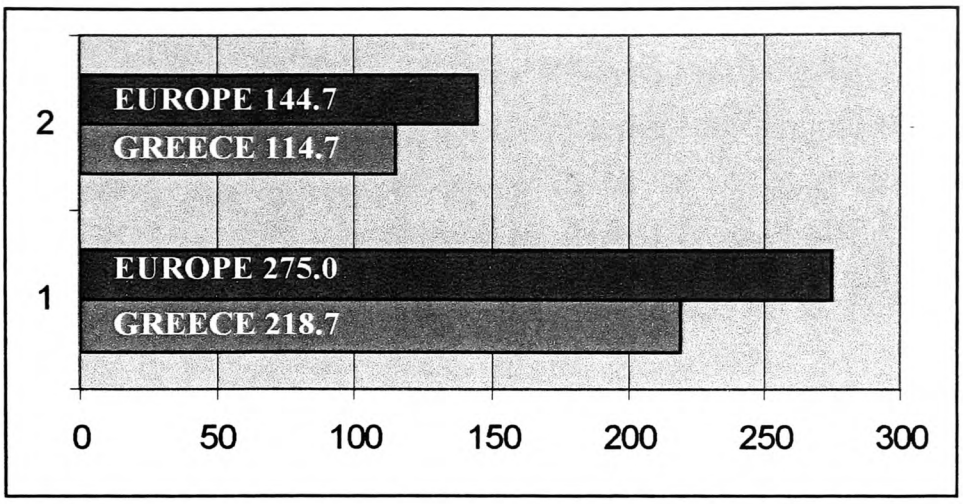


Figure 2.4 Age-standardised cancer mortality rates for Greece and Europe (1995)

Black *et al.* (1997) reported that in Greece there were in total 26,574 new cancer cases during 1990. Lung cancer is the most common cancer among men (28.4%) and breast cancer among women (26.8%). More than three quarters of the cases of lung cancer occur in men who are over 40 and for almost twenty years lung cancer has been the most common type of cancer among men over 40 years in Greece. Orphanidou *et al.* (1994) investigated whether epidemiological data of lung cancer have changed during recent years. These authors reviewed the hospital records of 400 patients with lung cancer who were diagnosed in the years 1982-1983 and 400 patients diagnosed in the years 1992-1993. No significant change was observed in cancer frequency among age groups during that period. Cancer of the lung remains the leading cause of death from malignant neoplasms in the 45-69 age groups (www.ypyp.gr).

In Greece, during 1982, cancers were responsible for a fifth of all deaths (19.7%), while in 1999, 23,419 deaths were reported because of cancer, showing an increase to 23% of all deaths (www.statistics.gr). In 1999, 5,782 people died from lung cancer, meaning that a quarter of all cancer deaths were caused by lung cancer. Breast cancer

caused more than 1,000 deaths every year during the period of 1981-1985. In 1999, the number of deaths by breast cancer have raised to that of almost 2000 per year. Deaths caused by breast cancer are increasing almost 4% every year, especially among the ages between 45 and 65 and more often in civic than rural areas (Dontas 1991). A recent publication by the Greek Ministry of Health (www.ypyp.gr) reports that primary causes of death from cancer for the total population (latest available data 1999) were cancer of the peptic and respiratory system (29% and 25% respectively).

Although Greece seems to rank low in cancer incidences and mortality among other countries in Europe, epidemiological data shows that there is a steady increase of mortality from all cancers during the period 1960 to 1985 (Katsougiani *et al.* 1990). More recent data also shows that the epicentre of the pattern of incidence of tobacco related cancers is moving from north Europe to south Europe (Black *et al.* 1997). In addition, cancer incidences are more common with increasing age and this particular issue will affect Greek health services in the near future. In 1993, 33.6% of the population was over 45 years old and the trend is that this percentage is increasing. It is estimated that the elderly population will increase by 10% during the next 30 years, meaning that one third of the population will be over 60 by the year 2020 (WHO 1998a).

According to Bray *et al.* (2002), Greece remains the European country with the lowest incidence and mortality rates. However, it must be noted that due to a lack of cancer registries in Greece, incidence rates have been estimated using registries from Italy and Spain (Vlachonikolis *et al.* 2002). Furthermore, the apparently low cancer mortality rate in Greece has raised some concerns. In Greece, information regarding the cause of death is gathered from death certificates, as in most countries. After investigating 756 death certificates in the rural Crete area Lionis *et al.* (2000) found that the most common cause of death reported in the certificates was cardiac arrest or cardiopulmonary insufficiency. The authors suggested that these were not causes of death but mechanisms of death in a vast number of diseases. It is possible that the low mortality rates in Greece are misleading, as patients who have died because of cancer might have been registered as deaths from cardiopulmonary insufficiency. The incidence and mortality rates may in fact be much higher (Lionis *et al.* 2000).

It is generally accepted that the needs and priorities in cancer control can not be determined without a complete and reliable cancer registration(International Association of Research in Cancer 1996). Between 1930 and 1940, cancer registration programmes began as a continuous recording of patients with cancer and an aim of producing reliable statistics about cancer morbidity and mortality. It appears that there is no national cancer registry in Greece. An effort to create a national cancer registry in the early 1990s did not succeed. However, for epidemiological purposes a local cancer registry in Crete was established in 1992, but this initiative has not been adopted by other parties in Greece (Vlachonikolis 1998).

2.1.5 Human Resources and Education

In 1999, almost 59,000 health professionals were employed in public and private hospitals in Greece, of which there were a total of 22,698 physicians, representing 38% of all health professionals employed (www.statistics.gr). Over the past 30 years, the number of trained doctors has increased significantly in Greece. The overall ratio of 210 inhabitants per doctor is one of the highest in the European Community. Greece also tends to record the highest ratio of specialists across the European Union (Eurostat 2000). Despite the introduction of new reforms, the regional distribution of doctors remains uneven with 58% of the doctors employed in the greater Athens and Thessaloniki area (Sigalas and Petraki 1999).

In 1999, 33, 376 nurses of all levels were employed in public and private hospitals in Greece. Only 40% of the nurses working in hospitals were fully qualified, with the majority working as 'practical nurses' with no formal training and a low level of general education. The ratio of nurses to population is one of the lowest in Europe, the overall ratio being 950 inhabitants per qualified nurse. A study by Plati *et al.* (1998) which aimed to register all working nursing personnel in Greece, found that the number of nursing personnel was 35,715, while the need was estimated to be 62,000.

According to the Hellenic National Statistical Service's website (www.statistics.gr), in 1999, there were 703 medical personnel and 1007 nursing staff in the four main cancer hospitals

In 1997, in an effort to assess the medical education on oncology, a questionnaire was distributed to the participants present at the European School of Oncology Course on "Cancer Prevention and Cancer Education of Health Personnel" held in Ioannina, Greece. Responses were obtained from 29 participants who came from 13 countries of the Balkan and Middle East. Yet, the sample was biased as 12 of the 29 participants were from Greece and the authors failed to report the number of participants at the course. Robinson (1999), reporting on the results of this study noted that the teaching of oncology was compulsory for 24% of the schools and both compulsory and elective for 24% of the remaining schools. For the majority of the schools the teaching was followed by an examination. The results of this study are only indicative, but they show the need for improvement of undergraduate education in the field of cancer.

It is suggested that almost 50% of medical knowledge becomes obsolete after ten years, however Kardamakis and Pavlidis (1999) revealed that in 73% of 11 participating Balkan and Middle East countries, among them Greece, continuing medical education in oncology was not a formal part of medical education. However, continuing medical education in oncology was recognised as moderate to very important by 63% of the doctors or the medical schools in the same study. It was also acknowledged by 82% of the participating countries that continuing medical education can improve doctors' knowledge and skills.

A Greek study by Sanidas *et al.* (1993) attempted to evaluate the influence of undergraduate medical cancer education on students' attiyudes towards cancer. A questionnaire was given to 90 first and second year students and again to the same group of students when they advanced to their fifth and sixth year. Eighty-six students replied in the first questionnaire while only 45% of the 70 students who reached the second period responded to the second questionnaire. Sanidas *et al.* (1993) reporting on the results of this study revealed that students' knowledge improved through the years regarding cancer issues, although the changes were not significantly different. This was a small study and the results can only be indicative, however Sanidas *et al.* (1993) believe that the years of medical education do not equip students with the appropriate knowledge regarding cancer.

With regards nurses' education, it has been suggested that people affected by cancer should have access to nurses with appropriate experience and skills as part of the multi-professional healthcare team (RCN 1996). Nurses working in oncology hospitals might have the experience and appropriate skills to care for cancer patients however, nurses working in general hospitals do not seem to have the appropriate skills and experience. McCaughan and Parahoo (2000) assessed the self reported level of competency of 106 nurses in a general hospital in Northern Ireland when caring for cancer patients. The nurses in this study felt very confident providing physical care but their level of competency was reported lower for the psycho-social aspects of care. Corner and Wilson-Barnett (1992) reported the same results with 127 newly registered nurses when they conducted the same type of study in the UK. In Greece, a study by Savopoulou (1992) revealed that nurse students were not able to care for patients with cancer of the large intestine. These studies have relied on self assessments which could argued to be unreliable. Other sources of useful data should be employed as well, such as the views of patients on nurses' performance.

Savopoulou (1999) on a report for nursing oncology education in the Balkan and the Middle East notes that oncology nursing was taught as part of a medical or surgical course for the majority (67%) of nursing schools in the 11 countries. Greece was the country that offered the most extended separate compulsory oncology course among the Balkan and the Middle East countries (45 hours of theoretical and 45 hours of clinical training) during the basic nursing education.

In the same report, the continuing oncology nursing education was assessed in the same 11 countries. Patiraki-Kourbani (1999) reported that all countries responded acknowledging that a systematic continuing education in oncology nursing existed. In Greece, a course that was run by the University of Athens for three years, supported by the 'Europe against Cancer' programme, was identified as a possible example of best practice which could be transferred across Europe to other member states (Jodrel 1997). However, this course is no longer in existence. The oncology sector of the Hellenic Association of Nurses is active and organises short courses for nurses with an interest in oncology nursing, although these are not compulsory.

Concluding, it must be acknowledged that the Greek healthcare system has not evolved as it might have been hoped when it was established in 1983. The shortage of health professionals and the lack of appropriate education only seem to aggrevate the existing problems within the health system. Polyzos and Yfantopoulos (2000) suggest that the Greek NHS suffers from a maldistribution of personnel, absence of decentralisation policies and inadequate training. It is anticipated that these problems will be also reflected in the area of cancer care provision, which is described in the following section.

2.2 CANCER CARE PROVISION

Cancer care in Greece is provided mainly in hospitals and only a minority of patients receives care in the community. This section describes the main cancer services provided in Greece.

2.2.1 Primary Cancer Care Services

Primary care services refer to the wide range of community based health services. According to the 1983 healthcare reform, primary healthcare was to be provided by health centres and their provincial clinics in both rural and urban areas in Greece. All health centres proposed by the legislation for rural areas were constructed and began to offer primary health services during the 1980s to their catchment areas (14,000 to 15,000 population on average). In urban areas, the provisions of the law did not materialise resulting in the operation of a variety of provider settings. Due to staffing, financial and organisational problems, health centres' actual performance has fallen short of expectations. According to a Ministry of Health study, the number of occupied doctor posts in primary health settings was 50% lower than the required number (Moraitis 1995).

However, the main problem is with the organisation of primary care in urban areas. A law in 1997 proposed the establishment of primary healthcare networks around the health centres based on the family doctor. Such networks have not yet been established due to a lack of human resources. In the 1990s, the number of trained general practitioners was approximately 750, despite the estimated need of 5,000 to 6,500 according to international standards (Moraitis 1995). In urban areas, the out-patient departments of public hospitals fall into the category of NHS provided primary healthcare (Petridou *et al.* 1999). Out-patient departments usually operate on an appointment basis and all persons are entitled to use these services. Insurance funds like the Institute of Social Insurance (IKA), own and operate their own primary healthcare facilities especially in urban areas.

Primary care services for cancer patients are no different to these existing in general in Greece. The first contact patients have with a doctor is either in a health centre, or

the outpatients' clinic of a hospital (Hellenic Anti-cancer Society 2003). If there is a strong belief that somebody has cancer, the first contact will usually be at the outpatients' clinic of one of the special oncology hospitals, at one of the University or regional hospitals. This means that cancer patients, if they receive treatment in one of these hospitals, will have to return for follow up even if they are living far away. Furthermore, the existing system does not provide a family doctor who would direct patients to the appropriate place for better assessment and treatment. As cancer patients have to find their own way in the system, they usually prefer to be treated in big regional, University or special cancer hospitals (Hellenic Anti-cancer Society 2003).

2.2.1.1 Cancer prevention

Primary care services, apart from being the first point of contact for healthcare users with a suspected malignant tumor, offer other services such as cancer prevention. Cancer prevention is of particular importance because almost 75% of human cancers are related to lifestyle and at least 50% of all cancers appear to be potentially preventable by changes in individual behavior (Tubiana 1993). For the purposes of this review, Kendall's (1989) approach to cancer prevention will be used, which is based on an earlier framework by Caplan (1961). The 'Caplan framework' encompasses primary, secondary and tertiary prevention. According to Kendall's (1989) cancer prevention framework, primary prevention focuses on reducing risk, secondary prevention focuses on screening for disease and tertiary prevention focuses on prevention of further disability in established disease. The following sections will describe the proposals by WHO and in particular the European directions regarding cancer prevention at the three levels and specifically the situation relating to the health system in Greece.

2.2.1.1.1 Primary prevention

Primary prevention is to avoid the disease before it starts and can be applied to some cancers where a cause is known (Charlton 1994). WHO (1995) proposes three areas of consideration in primary prevention; tobacco control, health education on lifestyles (diet, sun exposure, sexual habits) and Hepatitis B vaccination.

With a significant positive correlation between cigarette smoking and lung cancer (Henderson *et al.* 1991), primary prevention seems a logical approach. In contrast to most countries in the European Union (EU) where per capita cigarette consumption has decreased, the annual adult (age 15+) per capita consumption of cigarettes has risen steadily in Greece since the 1970s (WHO 1997). A recent report on the percentage of smokers in different countries suggests that in Greece, male smokers' (18 years +) percentage is 46% and the percentage of female smokers is 28% (OECD 1999). Given the high and increasing rates of tobacco consumption from the 1970s to the 1990s, marked further increases in tobacco-related mortality are anticipated in the coming decades.

The Tobacco Control Resource Centre (TCRC) reports that the problem of smoking is quite evident among physicians as well (TCRC 2000). A study by Polyzos *et al.* (1995) of 148 hospital physicians, revealed that 49% were smoking more than 20 cigarettes per day. Although the study involved physicians from only three Athenian hospitals, the results are of particular importance as, in the same study, it was revealed that only half of the physicians who smoked would get involved in smoking cessation counselling, whereas all non smoker physicians would counsel patients to stop smoking. This result was highly significant at $p<0.001$ (Polyzos *et al.* 1995).

WHO (1995) has proposed a three component strategy for tobacco control. Education, legislation and national leadership. Yet, the educational component is underdeveloped in Greece. WHO (1995) suggests that school children should be educated on tobacco control. However, the initiative is left to the teachers. Health professionals in primary health care settings who are responsible for developing and offering health education seminars are not enough to promote smoking cessation.

Government and non government organisations conduct regular public information initiatives relating to the dangers of tobacco use with no legislative mandate from the Greek government (TCRC 2000). The legislation in Greece is similar to that of other European countries regarding tobacco advertising and distribution restrictions. Government and non-government organisations voluntarily have formed a national coalition to address issues related to tobacco control (TCRC 2000). However, the

increasing number of smokers indicates that the prevention policies are inefficient. More research is needed in this area in order to develop more effective strategies in Greece.

Another area in which primary prevention programmes should focus on is education on healthier diets, sun exposure and sexual habits. Epidemiological data show that the incidence of cancers linked to dietary factors, particularly cancer of the large bowel, breast, endometrium and prostate is lower in Mediterranean countries than in Scandinavian countries and the United Kingdom (Coleman *et al.* 1993). The traditional diet in Greece includes most of the characteristics that are considered to contribute to the prevention of cancers such as colon cancer, oesophageal cancer and prostate cancer (World Cancer Research Fund 1997). These include a diet characterised by high consumption of foods of plant origin, relatively low consumption of red meat and high consumption of olive oil (Trichopoulou *et al.* 2000).

Non melanoma skin cancer is very common in Greece due to the country's climate. Stratigos *et al.* (1996), based on their retrospective study, report that non melanoma skin cancer is increasing in Greece, although data on its true incidence is lacking. Efforts have been made by the Hellenic Society of Dermatology and Venereology to educate the Greek population regarding the sun induced skin cancer. However, there has not been comprehensive analysis of the results of these efforts. Katsabas *et al.* (1998) report that, despite the warnings and the education, people do not seem to have changed their beliefs and attitudes towards sun exposure in Greece.

Hepatitis B may lead to liver cancer. WHO (2002) has proposed the education on sexual behaviour and vaccination against HBV. Since 1998, Greece has decided to introduce the vaccination against HBV to the National Programme of Vaccinations aimed at all the new born infants and children before the age of puberty (Noula and Theodosopoulou 2001).

2.2.1.1.2 Secondary prevention

According to Perkins (1992) the whole ethos of secondary prevention lies in screening. This is very important especially in cases where early treatment can improve the prognosis (Charlton 1994). The European Union's Advisory Committee on Cancer Prevention (ACCP) has addressed the issue of cancer screening and it offers recommendations for screening to the member countries of the European Union (ACCP 2000). According to the committee, cancer screening should be offered only to healthy people and only if it is proven to decrease the disease specific mortality or incidence, if the benefits and risks are well known and the cost effectiveness of the screening is acceptable. At present, the screening methods that meet these criteria are:

- Papanikolaou smear screening for cervical abnormalities starting at the latest by the age of 30 years;
- Mammography screening for breast cancer in women aged 50-69 years;
- Faecal occult blood screening for colorectal cancer in men and women aged 50-74 years (ACCP 2000).

There are more screening tests available for other types of cancer, however their efficacy has not yet been established.

2.2.1.1.2.1 Cervical cancer screening

It is estimated that if all women attend and all detected lesions are followed-up every three years, cervical smear tests could prevent 90% of cervical cancers in a population (IARC 1986). The Advisory Committee on Cancer Prevention (2000) suggests that cervical cancer screening programmes in several countries have been very effective, especially in the age range of 30 to 60 years.

In Greece, there have been only two regionally organised screening programmes funded by the European Union and covered one area in northern Greece and another in southern Greece. Riza *et al.* (2000) described the programme in detail for both regions and explained how well it was accepted by the regional population. However,

they did not provide any results on the lesions detected. Despite the fact that Greece ranks lower regarding the incidence of cancer of the cervix among other European countries (Bray *et al.* 2002), the experience gained since the beginning of these programmes might be used by the appropriate governmental bodies to establish cervical screening services at a national level.

2.2.1.1.2.2 Breast cancer screening

Breast cancer screening facilitates early detection and includes age appropriate mammography, clinical breast examination (CBE), and breast self examination (BSE). Five year survival is high, around 95%, if the cancer is diagnosed at an early stage (Yarborough and Braden 2001).

Mousiama *et al.* (2001) suggest that Greek women are increasingly concerned about breast cancer but their sensitisation to its secondary prevention remains low. In a study among 16 European countries, it was revealed that among the 215 Greek women who participated in the study, with a mean age of 53.4 years, only 31% reported self breast examination and only 19% reported frequent checks (Veronesi *et al.* 1999). Mousiama *et al.* (2001) also suggest that women in rural areas are usually poorly informed about the potential possibilities and the benefits from early detection of breast cancer signs by monthly breast self examination.

In addition, Greek doctors and nurses are not fully aware of the value of self breast examination or of regular mammography examinations too. There is evidence that the level of knowledge among primary healthcare workers in Greece regarding breast cancer screening is not adequate. Patistea *et al.* (1992) reported that among 268 women health professionals working in primary healthcare settings, only 34.7% practised breast self examination themselves each month. The authors regarded this percentage as very low given that part of health professionals' role is prevention.

Breast cancer is the most common cancer among women in Greece (WHO 1997). However, there is no uniform policy for breast cancer screening and it is not nationally implemented (Mousiama *et al.* 2001). The Hellenic Society of Oncology with the financial support of the European Union started a pilot study in 1989 in order

to investigate the feasibility of developing a breast cancer screening programme in Greece (Garas *et al.* 1994). The acceptance of this screening programme by the population has led the Hellenic Society of Oncology to develop its own screening programme in 1992 in 13 prefectures of Greece, funded by the Ministry of Health, the Hellenic Cancer Institute and wealthy individuals. Since then, a total of 106,278 mammography examinations have been performed (free of charge). The results and the acceptance by the population indicate that screening programmes for early breast cancer detection coud be implemented throughout Greece (Mousiama *et al.* 2001).

2.2.1.1.2.3 Screening for other cancers

ACCP (2000) advises countries where colorectal cancer is a major health problem to consider faecal occult blood screening as a preventive measure. A pilot study conducted in an Athenian oncology hospital between 1980 and 1996 among 25,390 healthy individuals who undertook a faecal occult blood test, revealed that there was an increase in the percentages of the potential curable colorectal cancer. Mpesmpeas (1998) reported in this pilot study that the percentage of the potential curable colorectal cancers rose to 25.6%, from a previous figure of 7%.

With regards to prostate cancer, the effect of screening has yet to be established. Studies such as the European randomised study of screening for prostate cancer initiated in 1994 involving seven European Union countries is expected to publish its results in 2008 (ACCP 2000). In Greece, a study on the value of prostate cancer screening was conducted among 1,400 asymptomatic men who volunteered to participate after an advertisement in the local newspaper (Deliveliotis *et al.* 1995). The objective of the study was to assess whether it was worthwhile to screen asymptomatic men for prostate cancer and to determine the number of patients that could be cured after detection by screening. The researchers concluded that screening for prostate cancer cannot be justified until long term randomised studies can demonstrate that prostate cancer screening has a major impact on morbidity and mortality and until aggressive tumours can be distinguished from those with a benign course (Deliveliotis *et al.* 1995).

Although sporadic programmes exist, nationally organised cancer screening programmes do not exist in Greece. ACCP (2000) suggests that decisions on the implementation of cancer screening programmes should be made within the frame of the general priority setting on the use of healthcare resources in each country. The studies conducted on cervical and breast cancer screening in regions of Greece have been well received by the population and indicate the spread on a national level. However, the available healthcare resources and the low incidence of certain cancers may not justify the national spread of any cancer screening programme in Greece.

2.2.1.1.3 Tertiary prevention

At this stage of prevention the disease already exists, but there are still benefits to sufferers, by minimising the ill effects of the disease within the context of prevention (Cutler 1999). Textbooks and journals do not offer extensive information on tertiary cancer prevention. It is assumed that tertiary prevention in cancer refers to prevention of progress, recurrence or other complications (Mahon 2000). In the area of cancer, this could include monitoring for early signs of recurrence using tumour markers or detecting secondary malignancies early in long term survivors.

2.2.1.2 Home Care Services

A recent ambition in the care of cancer patients has been to decrease the duration of in-patient care. This has been done for economical reasons and to satisfy patient preferences (Lowenthal *et al.* 1996). Traditionally, cancer patients undergoing any type of treatment were hospitalized for several days. However, improved management of side effects has facilitated the transfer of these treatments from in-patient to out-patient settings (Johansson *et al.* 1999). Duffin (2001), reporting on the paper presentations from a European cancer conference, revealed that 36 of the 54 cancer patients who chose to be treated at home in a trial in the Stockholm area of Sweden were 100% satisfied with their care at home. Supporting evidence comes from a randomised controlled trial conducted in Spain which compared chemotherapy given at home for 45 patients and chemotherapy in an outpatient setting for 42 colorectal cancer patients (Borras *et*

al. 2001). The results showed that there were no significant differences in the use of healthcare resources for unplanned visits, while patients treated at home were more satisfied than those treated in an outpatient setting. As this study was only limited to a specific treatment for colorectal cancer, caution is needed when interpreting the results. Some forms of cancer require complicated treatment that may cause side effects that would not make home care a viable option.

A comparison study in Spain also supported the view that home care could be less costly. Subirana - Serrate *et al.* (2001) compared oncology home care (n=10) with hospital care (n=10) and revealed that the cost of home care for cancer patients receiving chemotherapy was 64% less than that of hospital care, although this difference was not significant. Despite the small sample, it was revealed that nurses devoted significantly more time to the home care patients than those cared for in hospital. Another advantage of home care revealed by this study was that patients did not have to leave their environment and had the support of their family.

In a Greek study, Christopoulou (1990) investigated 184 cancer patients who had experienced treatment either at home (51.6%) or in hospital (48.4%). Almost half of the sample expressed their wish to have their treatment at home and only 14.7% in hospital. Cancer patients who wanted to have their treatment in hospital, felt that it was not safe enough to receive it at home (Christopoulou 1990).

In contrast, home care for terminally ill Greek cancer patients has not been effective when survival was used as an outcome criterion (Tsamadouraki *et al.* 1992). A study, conducted in the 1980s in Athens, which compared the effectiveness of home care (n=101) with hospital care (n=101) for terminally ill cancer patients, revealed that home care was not effective when survival was used as an outcome criterion (Tsamandouraki *et al.* 1992). However, it is suggested that failure to acknowledge the quality of life variables and the patients' perception of the disease in this type of investigations are a weakness (Stommel *et al.* 1993).

It is surprising that only two of the four Greek oncology hospitals offer home care services for cancer patients. In Athens, 'Metaxa' hospital has offered home care

since 1979, with an emphasis on the care of terminally ill patients, and 'Agioi Anargyroi' hospital has been offering home care services since 1986 (Fragoulidou and Zyga 1999). A number of general hospitals also offer home care services including cancer patients. Despite the existing legislation for the development of home care services, home care in Greece is underdeveloped and the number of cancer patients who are offered home care is limited mainly due to the limited resources in the health care sector (Kerkstra and Hutten 1996).

2.2.2 Secondary and Tertiary Care Services

The Greek healthcare system is strongly hospital orientated. The weaknesses of primary healthcare services discussed in the previous section are associated with the significant use of hospitals' out-patient departments as a first point of contact, as well as secondary care in the form of specialised ambulatory medical services. The absence of a referral system gives the freedom to the patients to refer themselves to virtually any type of care. In addition, the multiplicity of provider settings offering both primary and secondary care makes the dividing line between primary and secondary care in the case of ambulatory services difficult (Petridou *et al.* 1999).

In general, cancer patients are treated in regional general hospitals which serve a population of between 1,000,000 and 1,500,000 and district general hospitals which serve a population of between 50,000 and 500,000. The regional distribution of secondary level hospital beds seems to be disproportionate, with the urban areas of Athens and Thessaloniki being better served (WHO 1996).

In the case of tertiary care, seven of Greece's 13 regions are covered by at least one large NHS University hospital, while the remaining regions are covered by the hospital of the neighbouring region, or Athens and Thessaloniki. As a result, there are cross-regional patient flows. It is not only the lack of regional services that create this regional flow of patients, but the wide spread dissatisfaction with the health services (Ferrera 1993) and the public lack of confidence in local health services (OECD 1994).

In 1999, among the 339 hospitals operating in Greece, there were only four special cancer hospitals. Three were situated in Athens, serving a local population of almost 4,000,000, but also offering a service to patients from a much wider area. The fourth was situated in Thessaloniki, covering the medical needs of more than 3,000,000 inhabitants of Macedonia, Thrace and those of neighbouring countries. These four hospitals provided a total of 1336 beds (www.statistics.gr).

In recent years, in addition to the services provided by special cancer hospitals, departments of surgical and medical oncology have been organised at the seven University Hospitals of Greece (Athens, Thessaloniki, Patras, Heraklion, Ioannina, Alexandroupolis, Larissa), offering cancer care to the patients of their local area. Most of the district general hospitals also provide oncology/chemotherapy treatment for the most common cancers, without always the involvement of an oncologist. Figure 2.5 shows the location of oncology and university hospitals in Greece. It is apparent that due to the geographical particularities of Greece areas such as the islands are not well covered by cancer services.

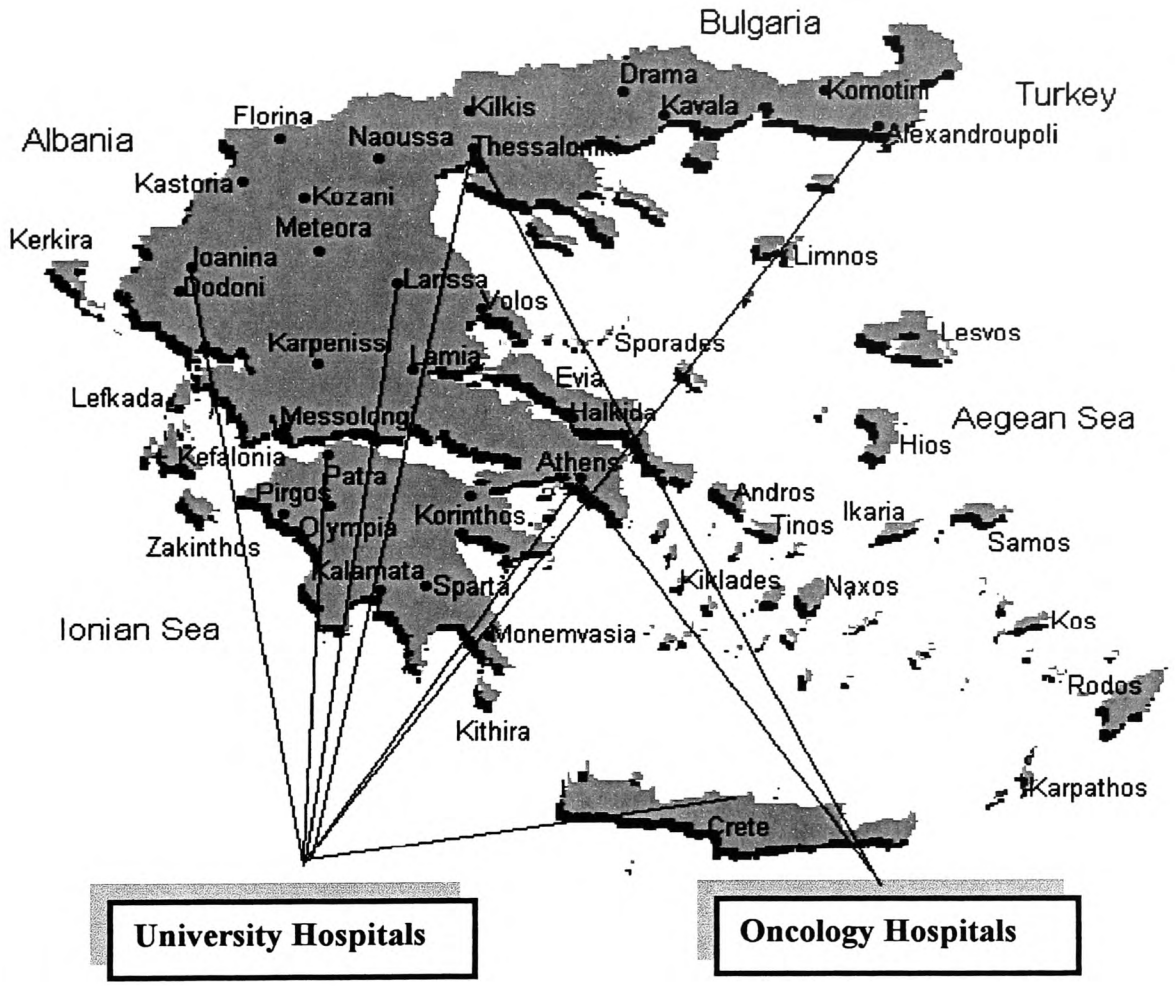


Figure 2.5 The location of oncology and university hospitals in Greece

Giokas (2001) on an effort to evaluate the resources available in secondary and tertiary care services in Greece concluded that there were deficiencies in the building infrastructure which had a negative impact on the quality of services offered. In addition, the biomedical technology was not satisfactory, since the hospitals were often unable to respond fully and independently to the needs of the patients for diagnosis and treatment and had to resort to the assistance of the private sector (Giokas 2001).

Furthermore, the non existent registry in Greece poses some problems when someone wants to evaluate the performance of oncology care or whether the treatment of cancer patients in secondary or tertiary health care settings has been effective. One of the methods to evaluate the efficiency of cancer treatment is through the monitoring of the 5 year survival rates for cancer patients (Welch *et al.* 2000). Cancer treatment cannot be evaluated in this way in Greece due to the lack of a national cancer registry. However, directors of clinics have periodically published results from small samples. For example, Vorgias *et al.* (1998), reporting on the results from a study among 38 women with stage I breast cancer (comprising only the 8.3% of the total breast cancer patients to this specific clinic), revealed that the 10 year survival rate was 100%.

2.2.2.1 The debate over regional and local provision of cancer services

In many countries, access to effective cancer management varies. In the UK, scientists have described access to effective cancer care as a lottery with wide variations in the treatments being offered even for common malignancies such as those of the breast, bowel and lung (Kunkler 1997). One of the ways to overcome this problem is to offer specialist cancer care in cancer centres, which means the centralisation of cancer care mainly in urban locations. Since the acceptance by the British Government of the recommendations made by the Expert Advisory Group on Cancer (Department of Health 1995) who advised the centralisation of specialist cancer services, considerable services tend to be offered in large specialist cancer centres. The rationale for re-organising cancer services in UK was to have advantages in terms of concentration of clinical expertise, enhancement of the ancillary facilities available, rationalisation in the provision of expensive specialist equipment, and in improving clinical outcomes (Payen and Jarrett 2000). However, the centralisation of

special cancer services means that, for many patients, care will be provided at a considerable distance from their home and their family.

Costain-Schou and Hewison (1999) suggest that the main problems arising from the centralisation of services are the potential stressors in terms of psychological adjustment, or a barrier to seeking appropriate care (poor compliance or uptake of treatment). There is an assumption that the greater the distance to be travelled, the higher the incidence of psychological morbidity and the poorer the compliance with treatment (Baider *et al.* 1996, Guidry *et al.* 1997).

With regards to the psycho-social distress caused by travelling far for treatment, an Israeli study (Baider *et al.* 1996) among Russian immigrants (166 cancer patients and 288 healthy individuals), revealed that having cancer and being far away from home for treatment was psychologically distressing. However this study did not investigate other variables such as the extent to which this psychological distress differed from that of people with cancer who have family to support them. Another study by Davis *et al.* (1998) conducted in rural areas of South Australia assessed the needs of 80 women with breast cancer. Their findings showed that 90% of the women spent a mean of 6.79 weeks away from home for treatment and 89% of them reported a lack of social and practical support. However, these studies have limitations as the former focused on immigrants, who may had been already distressed by experiencing adjustment problems, and the latter on rural areas of South Australia, where patients have extremes of distances to travel to treatment. However, a Canadian study suggested that giving cancer diagnosis and treatment nearer home could both save money and increase patient satisfaction (Martin *et al.* 1995).

With regards to the effect of travelling on uptake of treatment, a study conducted in the south of England did not reveal any statistically significant change in uptake of palliative radiotherapy with increasing travel time to the centre of treatment (Cosford *et al.* 1997). However, in this study, the longest travelling time was just over an hour, so generalisations cannot be made to more rural areas. By contrast, an American study of 593 cancer patients from different origins by Guidry *et al.* (1997) suggested that for 51% of Blacks and 66% of Hispanics, transportation was perceived as a barrier to treatment. Desoubeaux *et al.* (1997) also included distance as a variable in their large investigation of social and environmental influences on survival from

colorectal cancer in France. Farm workers of both sexes were found to have the poorest survival rates, implying that farm workers had to travel far for treatment, which may have affected their compliance with the treatment.

Cancer patients who have participated in focus groups, have revealed that they would travel anywhere if they knew that a place is acknowledged for its expertise and excellence (Department of Health 1996, National Cancer Alliance 1996), although they would prefer nearby hostel provision and improved parking facilities. Carers, who usually provide transport for cancer patients to and from hospitals, also were found to hold the same views. A carer in a study by Thomas *et al.* (2002) reported that:

"*...I can drive 82 miles a day every day for a year if it is going to do any good*" (p537).

Baird *et al.* (2000) questioned the centralisation of cancer services in rural areas in Scotland. They revealed that in their rural practice consisting of 32 cancer patients, of the 11 who died, they had survived an average 165 days after the diagnosis, of which 22 days (13% of their remaining life) was spent travelling to hospitals. Focusing on oesophageal cancer services, Milne *et al.* (2000) conducted a study among patients with biopsy proven oesophageal cancer who had surgery either at the district general hospital (60 patients) or the regional cardiothoracic unit (53 patients). They reported that survival rates were not necessarily improved by centralisation of services and the quality of service was poorer. However, there was higher postoperative mortality for the patients in the district general hospital, but it was not significantly different. Another study among patients with colo-rectal cancer in the Manchester area showed similar 5-year survival figures for all causes of death for those treated at district general and teaching hospitals (Kingston *et al.* 1992). However, it is suggested that better results on survival rates are achieved when patients are seen by multi-disciplinary teams of surgeons, radiologists, pathologists and oncologists for an initial decision on management once the diagnosis has been established (Harries *et al.* 1996, Kunkler 1997).

With regards to travel in order to receive treatment the literature is inconclusive and contradictory. Yet, having to travel to receive cancer treatment appears to be an

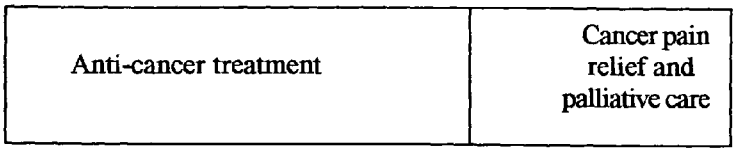
inconvenience for patients and may in certain situations be perceived as a barrier to patients' compliance with treatment.

2.2.3 Palliative Care Services

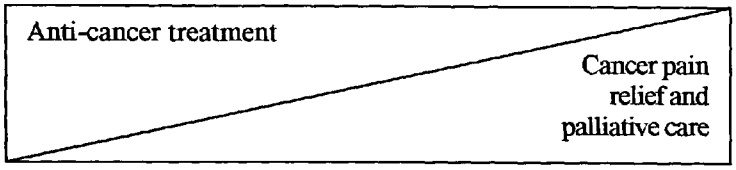
Palliative care developed as a result of an increased refinement of symptom control, particularly pain control in clinical settings during the 1950s and 1960s (Small and Rhodes 2000). Many of these advances were then taken up and further modified by the modern hospice movement, which developed after the opening of St Christopher's Hospice in London in 1967. WHO (1990) defines palliative care as the active care of patients whose disease is not responsive to curative treatment. Increasingly palliative care is seen as an integral part of all cancer patients' care. The principles of palliative care apply across all conditions and in all settings (Department of Health 2000a). Palliative care is not just a discrete intervention. It is an ongoing process, covering not only the control of pain but also other areas such as psycho-social and spiritual care and self esteem. Caring within the palliative approach focuses on the needs of patients and their families through a variety of means.

WHO's (1990) position is that the resources for palliative care should be increased, even at the expense of resources made available for anti-cancer treatment. WHO recommended the increase of resources for palliative care at the expense of treatment as world health statistics have shown that two thirds of the cancer patients were incurable (Stjernsward 1993). Despite an overall five year survival rate of nearly 50% in developed countries, the majority of cancer patients will require palliative care (WHO 2002). Figure 2.6 shows the current allocation of cancer resources world wide and the proposals by WHO for developed and developing countries:

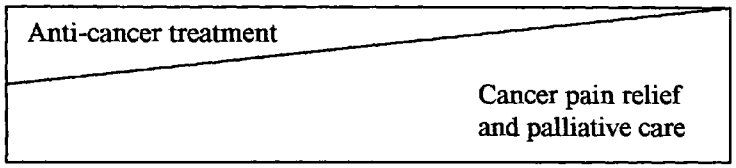
Present allocation world wide of cancer resources



Proposed allocation of cancer resources in developed countries



Proposed allocation of cancer resources in developing countries



WHO (1990) Cancer pain relief and palliative care. Geneva

Figure 2.6 Present and proposed allocation of resources for palliative care

Palliative care may be offered in a variety of settings. The National Council for Hospice and Specialist Palliative Care Services (1995) reports that palliative care is offered mainly by professionals based in hospitals and hospices. In recent years, emphasis has been placed on palliative care offered in hospices and at home rather than in other places such as hospitals and clinics (Rogers *et al.* 2000). To offer patients the choice of dying at home, or a place like home, is seen as an important outcome measure (Gaffin *et al.* 1996). Research evidence shows that over three quarters of patients show a preference of spending the last months of their lives either at home or in a hospice (Dunlop *et al.* 1989). Patients' carers have also shown dissatisfaction with hospital care for terminally ill patients. In one study, only half of the carers of patients dying in hospital were satisfied with the place of death (Addington *et al.* 1991).

Bruera (1998) suggests that home or hospice care is appropriate for more than 80% of cancer patients. It is also less expensive than acute hospital admissions. Whynes (1997) suggests that hospital stays are considerably more expensive than outpatient

and home care visits, days in nursing homes or in other non-hospital institutions. Appendix 1 provides studies that have focused on the cost effectiveness of palliative care compared to other forms of care. Palliative care seems to be effective as patients use the services and there is much support for the continuation of the services. However, convincing research evidence of the effectiveness of palliative care is limited.

Despite the efforts to assess the outcomes of palliative care, there is an agreement that research in palliative care poses particular problems for the researcher. The best research design in producing reliable evidence on the effectiveness of palliative care might be the use of randomised control trials. However, Higginson *et al.* (2003) have suggested that it is difficult to apply this method to palliative care. This claim is supported by Rinck *et al.* (1997) who examined 11 randomised controlled studies. All appeared to have methodological problems associated with recruitment of a study population, homogeneity, patient attrition, defining and maintaining interventions, and selecting outcome variables. Keeley (1999), commenting on the problems associated with randomised controlled trials in palliative care, suggested that it is unethical to withhold these services due to the lack of convincing evidence, as they are highly desired by cancer patients and their carers. Higginson (1999) added that the difficulties in gathering evidence about some aspects of palliative care should not be allowed to stand in the way of applying palliative care where its efficacy, patient and family satisfaction and cost effectiveness have been shown. However, strong evidence is lacking regarding the desirability and effectiveness of palliative care.

Based on the findings from palliative care studies, the attention of European health policy makers has begun to focus on end of life care. In 1999, the Council of Europe adopted a resolution on the protection of the human rights and dignity of terminally ill and dying patients and called for a legal entitlement to palliative care and in particular effective pain control for all individuals (Watson 1999).

2.2.3.1 Cancer pain control

One of the challenges palliative care faces is the control of cancer patients' pain (WHO 2002). Since the early 1980s cancer pain has been recognised as a major

public health problem and WHO (1990) has published guidelines, along with recommendations for palliative care, in order to alleviate the suffering of people with cancer pain. Stjernsward (1997) suggests that controlling pain is among the most pragmatic, humane and realistic goals for health intervention in developing countries.

Despite published guidelines for pain management, many palliative care patients have considerable pain and receive inadequate analgesia. The following table (2.1) summarises the findings of studies reporting pain prevalence for patients receiving palliative care across different settings:

Table 2.1 Prevalence of pain in patients receiving palliative care

Setting	Author	No of patients	% pain
Home	Doyle (1980)	268	80
Home	Wilkes (1984)	262	52
Community & hospital	Hockley *et al.* (1988)	26	69
Home to hospice	McDonnell (1989)	50	68
Community and hospital	Higginson & Hearn (1997)	695	24
Home	Mercadante *et al.* (2000)	211	47
Day care	Goodwin *et al.* (2003)	40	25

These studies present the incidence of pain for patients treated in different settings, however, these results need to be interpreted with caution as the authors fail to describe the pain in terms of its severity, location and duration. It is worth noting that these studies show that the location of the delivery of pain management is not critical. In one small scale Greek study of pain incidence among 220 cancer patients, 61% reported high levels of pain, 21% mild pain and 10% low levels of pain. However, it is surprising that only 102 of the patients (less than 50%) were receiving any analgesics at all (Mystakidou *et al.* 1999).

An Australian study by Chan and Woodruff (1991) examined the needs and the results of treatment for patients with terminal cancer who were admitted to a general hospital. Although pain was managed adequately for two thirds of patients, for the

remaining one third, its management was inadequate. Reasons given for inadequate pain management included the lack of medical expertise in the use of analgesics. That would be the case in Greece, as Mystakidou *et al.* (1998) in a study of 1200 Greek physicians, revealed that 80% of the physicians felt that their education in cancer pain relief was insufficient. In the same study, a large percentage of physicians (42%) were reluctant to prescribe opioids for cancer pain due to concerns about physical dependence and addiction. In Israel, Sapir *et al.* (1999) in a study of 236 medical physicians revealed the same concerns about addiction for cancer patients. Yet, the actual incidence of addiction and physical dependence is known to be less than 1% (Clarke *et al.* 1996). It is acknowledged that the control of pain for cancer patients is inadequate. However, evidence suggests that the task of controlling it is not impossible (WHO 1990, Portenoy and Lesage 1999).

2.2.3.2 Psycho-social care of cancer patients

Psycho-social care is regarded as an essential aspect of palliative care (WHO 2002). Historically, clinicians viewed the emotional distress associated with cancer as normal and a typical consequence of the disease. However, currently it is regarded as a problem in need of treatment (Fox 1995).

Many studies have documented the prevalence of psychological disturbance in the population of cancer patients. Massie and Hollands (1990) suggested that approximately 50% of cancer patients could be expected to experience normal stressful reactions to diagnosis and treatment, whereas the remaining 50% might have psychiatric problems, including adjustment disorders, depression and anxiety.

Depression is an affective state affecting at least 6% of the general population and it has been suggested that medical illness is associated with a 41% higher prevalence rate of depression (Wells *et al.* 1988). With regards cancer patients, the prevalence of depression ranges from 19% among 808 patients with terminal cancer (Kathol *et al.* 1994), to 31% among 105 women who had undergone gynecological surgery for cancer (Corney *et al.* 1992). Sellick and Crooks (1999) report that depression levels may vary depending upon the tools used to assess or screen for depression, the type of cancer, the gender and the age of the patients. Zabora *et al.* (2001) added to the

available research by studying the prevalence of psychological distress among 4,496 cancer patients and the variations in distress among 14 cancer diagnoses. The overall prevalence rate of distress for the large sample in this study was 35.1% and the rate varied from 43.4% for lung cancer to 29.6% for gynaecological cancers.

On the contrary, in an Australian study, Pascoe *et al.* (2000) reported low depression prevalence rates among cancer patients. In this study, only 7.1% of the 504 patients from four Sydney oncology outpatient departments reported high depression levels. The sample consisted of males and females with a range of cancers at different stages and different activity levels. Low depression prevalence rates (14%) were also observed in a South African study of 456 cancer patients attending out-patients clinics in a hospital (Berard *et al.* 1998) and a British study of women with advanced breast cancer (9%) (Bukberg *et al.* 1984).

It is worth noting that all the studies that have showed a low prevalence of depression among cancer patients, have used the Hospital Anxiety and Depression Scale (HADS) which has been criticised for having some limitations. The HADS contains 14 items and consists of two subscales measuring each of anxiety and depression. Each item is rated on a four-point scale, giving maximum scores of 21 for anxiety and depression. Hall *et al.* (1999) suggest that using the recommended threshold ≥ 11 for establishing a case of depression, the sensitivity of the HADS is very low.

Zabora *et al.* (2001) suggested that whatever tools are used to assess depression, anxiety and distress among cancer patients, the existence of psychological problems within the population of cancer patients is well documented. McQuellon *et al.* (1996) suggest that patients with cancer and their families may demonstrate a wide range of psycho-social needs, from the need for basic emotional support to intensive psychological services, provided by professional psychologists. Simpson *et al.* (2001) in a randomised controlled trial have shown the importance of psycho-social interventions provided by professionals for cancer patients. For the group of 46 breast cancer patients, who received a psycho-social intervention apart from the usual psycho-social care, improvement was observed in depression levels and quality of life and decreased levels of health services use. The available research on psycho-social

interventions for cancer patients has shown a large treatment effect based on psychosocial interventions offered by professionals (Sellick and Crooks 1999).

Other research has focused on the effect of psychotherapy groups as an intervention on cancer patient survival. Two randomised controlled studies have revealed a difference in survival among the control groups receiving standard care and the groups receiving the psychological intervention (Spiegel and Cordova 2001, Fawzy *et al.* 1993). In both studies, the intervention groups survived longer than the control groups. However, a study by Illnkcy *et al.* (1994) which involved 124 mixed cancer patients randomly assigned either to an intervention group (93) or to a control group (31) receiving no intervention, did not reveal any significant difference in survival. These studies have been criticised as they failed to follow the changes in patients' health and life style between the ending of the intervention and death. If there were any changes during this time, these could have influenced the findings (Bottomley 1998). The sample sizes in these particular studies place further limitations on the results. Indeed, Fox (1995) noted that in the analysis reported by Fawzy *et al.* (1993), the removal of one death from the control group would make the results insignificant. On this basis, caution is needed regarding the possible survival benefits conferred by group interventions.

Although psycho-social problems among cancer patients are well documented, health professionals fail to understand the extent of the problem. Health professionals either overestimate or underestimate cancer patients' level of psycho-social problems and their need for support. Newell *et al.* (1998) reported that, in their study of 204 cancer patients and five oncologists who treated them, patients' scores on the HADS indicated rates of clinical anxiety and depression similar to those perceived by the oncologists. However, the oncologists could not accurately identify the individuals affected. Furthermore, nurses seem to overestimate the psycho-social problems of cancer patients. Fincammon (1995) analysed nurse inpatient psychiatric referrals in a cancer centre through a retrospective chart review. Thirty two out of the 102 records reviewed were referrals for depression (31%), however only seven of the 32 cancer patients (6.9%) actually had a major depressive disorder. All these denote that a screening method is needed to evaluate cancer patients level of psychological distress during the trajectory of cancer.

As only some of the cancer patients will need professional psychological support, the remaining patients will have to be supported mainly by the nurses in the place they are treated. The Royal College of Nursing (RCN 1991) has stressed the need for nurses to be prepared to recognise the symptoms and signs of depression and anxiety among cancer patients and, in the case of mild anxiety and depression, to initiate appropriate strategies for their reduction. Although nurses treating cancer patients favour the emotional aspect of caring than the task-orientated caring (Larsson *et al.* 1998), it seems that their basic education has not prepared them adequately for this role. Roberts and Snowball (1999) report that many of the psycho-social skills nurses use are neither systematically applied nor formally taught,

"...*they are just basic skills that you can learn, and you learn as you go along in nursing*" (p45).

Cancer can also create irreparable damage to a person's social functioning (Bertero 2000). Having a malignant disease may affect a person's relatives, work colleagues, close friends, the ability to work and care for one's family. Researchers increasingly regard social support as critical to cancer patients' psycho-social well being (Dow 1995). When people are diagnosed with cancer, the need for social support increases, and these needs can be met by family, friends, health professionals and others (Bottomley 1995). Research shows that cancer patients, when faced with personal problems, tend to seek help from their relatives and their friends rather than health professionals. Bertero (2000) revealed in her study of 218 Swedish patients with cancer related to sexual organs and breasts that only 3.5% would ask for advice on social support from health professionals. These findings are consistent with normative data selected by Norbeck *et al.* (1983), showing that 90% of the subjects did not cite any healthcare professional as a provider of social support.

If this is the case, health professionals and especially nurses have an important role in relation to enhancement of supportive relationships. The nursing role should be to assess cancer patients informal support needs, and preserve support by minimising disruption and maximising support, for example through support

groups. WHO (2002) suggests that effective communication between cancer patients and health professionals is the key to psychological support.

2.2.3.2.1 Communication with cancer patients

The literature demonstrates evidence that effective, patient-centred communication is associated with many important and meaningful health outcomes, including adherence to drug regimes and diets, pain control, resolution of physical and functional symptoms, improvements of physiological measures and psychological functioning of patients (Stewart 1996).

Although communication is a feature of the care relationships with health professionals of all disciplines, the research suggests that communication with the physician remains critical to the cancer patient, and therefore communication problems between physicians and patients are likely to create the greatest distress (Thorne 1999). Communication problems can start as soon as the first consultation with the oncologist, who is faced with the dilemma of disclosing a cancer diagnosis to a patient. The problem of telling the truth to the patient has a long history and it has been a widely debated issue in cancer care (Krisman-Scott 2000). The main problem is the conflict between the right of a person to know the truth and to maintain his autonomy and the protection of the patient from psycho-traumatic information.

Giannopoulou (1992) in her study on the patient's right to be told the truth cites Kant (1909) and his writings 'on the supposed right to tell lies from benevolent motives' that it is a mistake to lie, as lying may have an effect on other people. In addition, Bok (1999) maintains that lying affects the whole society and that there needs to be a level of truth for the society to exist. Jackson (2001) suggests that truthfulness matters because it is necessary to support trust and co-operation, without which social life would be radically impoverished. In the case of communication between health professionals and patients, truthfulness helps the patient to remain autonomous and creates a meaningful partnership. Faden and Beauchamp (1986) observe that autonomy is the most important value which has been given emphasis in medical and research ethics in the last decades, and involves the patient's right to participate in the choice of treatment and the right for information.

Opposing views suggest that withholding the truth can help patients to overcome the fear and the depression of a potential cancer diagnosis. In Greece, Mystakidou *et al.* (1996) reported that 78% of the 228 doctors who participated in their study doubted the wisdom of giving bad news to certain patients in the belief that it might be harmful to them. Some patients may not be able to cope with the information, will give up hope that is necessary to their proper functioning and become depressed or otherwise disadvantaged. Furthermore, Papadimitriou *et al.* (1998), in a sample of 120 Greek cancer patients, have revealed that informed patients were more anxious (60%) and more sensitive (73%) than non-informed patients (31% and 61% respectively). However, the authors failed to describe what type of information the informed patients had received and the concept of sensitivity was not defined.

The first study to investigate the beliefs and attitudes of the public regarding cancer in modern Greece was conducted in the 1970s by the Hellenic Anti-cancer Society. In this study, 71% of the 3,154 healthy participants did not want to know the truth if they had cancer (Hellenic Anti-cancer Society 1987). Rigatos (1997) also reported that in the first public discussion on the subject of informing the cancer patient that took place in Athens in 1974, more than two thirds of the doctors engaged in oncology supported the opinion of not telling the truth. The beliefs and the attitudes of 110 Greek physicians working in cancer and university hospitals were first studied in 1980 by Manos and Christakis (1981). The results of the small scale study showed that 73% of the participating physicians never or rarely announced the diagnosis of cancer to the patient.

The most recent studies in Greece regarding physicians' attitudes towards telling the cancer diagnosis to patients show that attitudes have not changed. A study by Kordiolis and Regatos (1990) has revealed that 87% of 120 physicians, mainly from Athens, would not inform patients if they were diagnosed with cancer. In Giannopoulou's (1992) study of the patient's right to be informed, only one third of the 60 doctors who were working in a cancer hospital, revealed the diagnosis to their patients. In the same study, 42 out of 48 cancer patients did not know their diagnosis whereas 48 out of 52 patients, who had other diseases, knew their diagnosis.

Another study by Mystakidou *et al.* (1996) showed that among 228 doctors, only 11% would disclose the diagnosis to all their patients and 78% had decided to communicate a diagnosis of cancer to some of their patients. The majority of the doctors (83%) disclosed the diagnosis to the patient's relatives initially, showing a break in the rule of the confidentiality of the doctor - patient consultation. A more recent study by Mystakidou *et al.* (1999) showed an increase in the number of doctors who revealed the diagnosis and prognosis to a cancer patient, 22% and 28% of 1,280 physicians respectively. Although a greater number of doctors currently disclose a cancer diagnosis, compared with the past, the number of doctors who would reveal cancer diagnosis remains low in Greece compared to other northern European and Anglo-Saxon countries or the USA.

In the USA, towards the end of 1970s, doctors' attitudes were different with a profound support on telling the truth. Novack *et al.* (1979) reported that 97% of the 264 physicians in their study would reveal a cancer diagnosis to their patients. Cassileth *et al.* (1980) also suggested that patients held similar views and 90% preferred full information about their cancer. These attitudes by the physicians in the USA have been linked to social changes like lesser stigmatisation of cancer, increased patient autonomy and improved therapeutic possibilities for several types of cancer (Novack *et al.* 1979).

The differences among cultures are also revealed in the following studies. A study of 260 gastroenterologists in all parts of Europe revealed that in northern Europe they would usually talk openly to the patient and (with the patient's permission) to their spouse. However, different views were held by gastroenterologists in southern and eastern Europe, who would usually conceal the diagnosis and prognosis (Thomsen *et al.* 1993). In Scandinavia, a study among 990 randomly selected Norwegian physicians showed that 81% provided full information of the diagnosis to cancer patients (Loge *et al.* 1996), supporting the view that northern societies are more accepting of hearing the truth regarding a cancer diagnosis.

Mystakidou *et al.* (1996) suggest that most of the patients in Greece might not be ready for disclosure of the truth and this is probably why doctors' practices are similar. In their study, the decision to disclose the diagnosis depended on the

perceived personality (74%) and anticipated reaction (54%) of the individual patient, which is a subjective way to assess a patient's willingness to be informed. However, it is important to acknowledge the situation and take the appropriate measures when conducting research with cancer patients as is the case in this study. It should be noted that the cultural differences on informing patients in Greece have profound implications for this study. It must also be noted that under these circumstances, Greek healthcare users may have limited autonomy and participation in decision making in their own health or the development and evaluation of cancer services.

The lack of training in communication skills seems to be the main reason for ineffective communication between health care professionals and cancer patients (Fallowfield *et al.* 2001). Mystakidou *et al.* (1996) reported that almost 40% of 228 Greek physicians indicated that their medical education in communication skills and, in particular, breaking bad news was inadequate. Education in communication skills is essential in order that a partnership may develop between healthcare professionals and cancer patients. Maguire and Faulkner (1988) developed workshops for health professionals which led to participants acquiring most of the desired communication skills and relinquishing most of the undesired behaviors. However, a randomized controlled trial among 160 doctors from 34 UK cancer centres revealed that communication skills training did not have a significant positive effect on patient satisfaction (Shilling *et al.* 2003). It is anticipated that other factors may influence the communication process. More evidence is needed regarding the training of health professionals in key communication skills that will produce relevant changes in patients and health professionals over time.

2.2.4 Palliative Care in Greece

Mystakidou (1993), representative of WHO and the European Association for Palliative Care in Greece, reported on the efforts made by her team to establish the WHO cancer pain relief and palliative care programme in Greece. The Hellenic association for cancer pain relief and palliative care was established in 1991. She reported that in 1992, the first cancer pain relief and palliative care foundation was established in Greece with the aim of creating cancer pain relief and palliative care units and sub-offices in hospitals all over Greece. In 1993, the first university cancer

pain relief and palliative care unit was founded. This unit offers a full time service (with beds for cancer patients who need palliative care). It also offers educational opportunities for doctors and nurses who wish to be trained in this area. The author also acknowledged that Greek provinces have been deprived of both palliative care and home care services although there are efforts to improve the situation. Mystakidou (2001) in a more recent report, acknowledged the continuing lack of palliative care in Greece apart from the capital. However, efforts have been made to implement some aspects of palliative care with pain relief offered to out patient clinics in some hospitals.

The results obtained by testing the European Organisation for Research and Treatment of Cancer (EORTC) quality of life instrument on a Greek randomly selected sample of 120 cancer patients, from those attending the outpatient clinic of a palliative care unit in Athens, form an example of the effectiveness of palliative care from Greece. It showed a considerable difference between the pre-treatment scores and the scores obtained during palliative care. The mean scores for all the patients regarding their physical, cognitive, emotional and social functioning levels were increased during treatment, and the mean scores on the symptom scales had decreased for all the patients (Mystakidou *et al.* 2001).

Papadatou (2001) reports that in Greece palliative care services are limited providing physical care and comfort to a restricted number of patients, disregarding the psycho-social and spiritual aspects of a more comprehensive palliative and hospice care approach. It must be noted that two hospices were built in Greece by the Hellenic Anti-cancer Society in the 1960s. One was built in Thessaloniki and the other in Athens. Both were closed down in the 1970s as they were not meeting the palliative needs for which they were built. Currently the Hellenic Anti-cancer Society has formulated plans to operate two hospices, in the same areas, in the hope that knowledge and experience from other countries will help these hospices to serve their aims. Due to the limited provision of palliative care services, it is anticipated that many cancer patients may experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from healthcare professionals during the final stages of cancer. This can have a lasting effect on those close to the patient who

often carry the burden of care (Department of Health 2000b). This is of particular importance and has to be considered as in Greece family ties are strong and compensate for the lack of support by psychosocial services.

2.3 HEALTHCARE PROVIDERS' AND USERS' SATISFACTION WITH HEALTHCARE SERVICES IN GREECE

Since the establishment of the Greek National Health System in 1983, healthcare in Greece has not evolved as well as it might have been hoped. Ferrera (1993) reported on the European Commission's finding that only 25% of the Greek population was satisfied with the health system in Greece. A Eurobarometer study, conducted by the European Commission on attitudes of the population towards European Union and its policy with a sample of 1,000 persons from each member country, concluded that the percentage is even lower, reaching only 10.7% (EUROSTAT 2000). In other European countries, satisfaction with services is in most cases higher. For example in the UK the 'fairly' and 'very satisfied' citizens were almost 50% and in Finland 78%. In Greece, it is only in areas where University hospitals operate (for example, in Crete, Peloponissos and Heperus) that satisfaction rises almost to 40%, probably because of the proximity of high quality services.

The latest research on people's satisfaction with the Greek NHS was ordered by the Minister of Health in 2000. The research was undertaken by the Ministry of Internal Affairs and the sample consisted of 3,000 patients, 800 health professionals, and 2,000 citizens. Only 29% of the sample were satisfied with the Greek National Health System, while 68.5% were 'little' or 'not at all' satisfied (Komninou 2000). It seems that the voted reforms since the establishment of the National Health System in the 1980s have not made a noticeable difference.

A thorough search of current literature did not reveal any specific articles reporting on cancer patients' satisfaction of cancer care or services in Greece. It is difficult to establish whether cancer patients' satisfaction level of health services differs from a rather low level amongst patients in general. It is probable that if healthcare providers and users views were involved in the decision making process for the development and evaluation of healthcare services the dissatisfaction levels would be lower.

2.4 POLICY MAKING AND USER INVOLVEMENT IN HEALTHCARE

2.4.1 Policy Making in the Area of Healthcare

Over the last decades, health system change has been an almost universal experience in countries of the developed world. Governments are engaged in restructuring the funding, organisation and delivery of health services. Policy makers for the most part, provide the necessary input to governments and changes that are taking place. Policy making is commonly understood as a series of decisions made by an identifiable person or set of decision makers, who are charged with this responsibility (Trostel *et al.* 1999). According to West and Scott (2000), policy may refer to a set of specific plans for action or generally to the underlying organising principles guiding the development of that plan. Furthermore, policy in the area of healthcare could be defined as the principles, plans and strategies for action guiding the behavior of organisations, institutions and professions involved in the field of health, as well as their consequences for the healthcare system (West and Scott 2000). Cancer policy making is best described by the latter definition which implies the previous actions in the area of cancer care.

Policy making is a complicated task and there exist various models on policy making. Kingdon (1997) describes a model where issues become defined as problems when indicators, events or feedback force them onto the public agenda. Within this model policy outcomes are determined by different sources and can be influenced by various factors. An alternative view of the policy making process emphasises the importance of social relationships. This framework focuses on how the relationships among members of a community impact on the formation and implementation of policy (West and Scott 2000). However, most models of the policy process reduce it to a number of sub processes: identifying a problem of particular importance; formulating a response; implementing the policy; and evaluating the policy (West and Scott 2000).

Most of the literature has focused on the response formulation (decision making) and how this step could be as effective as possible. According to Dobrow *et al.* (2004) the two fundamental components of decision making are evidence and context. What constitutes evidence is a diverse issue within policy making as there are two

orientations; the philosophical orientation and the practical orientation. Within the philosophical orientation evidence is unconstrained by context and it has an inherent value with the potential to provide justification for decisions (Achinstein 2001). Therefore, from a philosophical orientation the quality of evidence is imperative with the supposition being that higher quality evidence should lead to higher quality decisions (Dobrow *et al.* 2004).

By contrast, the practical orientation to what constitutes evidence is context based, and evidence is defined with respect to a specific decision making context (Achinstein 2001). The practical orientation defines evidence less by its quality and more by its relevance, applicability or generalisabilty to a specific context (Dobrow 2004). The context based evidence is more suitable in the area of decision making as it takes into account the context which is integral to defining evidence. While the philosophical and practical orientations present different relationships between evidence and context, they do not directly address what constitutes context.

Dobrow *et al.* (2004) define the decision making context to include all factors within an environment where a decision is made. These factors may be very complex and often include the participants' personal views, the process of making a decision, the disease specific factors and political issues. The decision making context affects what constitutes evidence and how this evidence is utilised. According to West and Scott (2000), the context in some situations may provide constraints or limits for a decision and in other situations may provide an evidentiary basis for supporting or justifying a decision. A broader conception of evidence as described in the area of policy making might allow consideration of other issues such as obtaining information on healthcare providers' and users' preferences, thereby the context may alter the evidence base for the decision. Furthermore, Trostle *et al.* (1999) note that priorities and policy making can be influenced by organisations such as the WHO.

It is generally accepted that traditional political decision making is rather context orientated than evidence orientated (Dobrow *et al.* 2004). Evidence is only one of a number of factors that affect decision making, with contextual factors providing the basis for traditional political decision making (Black 2001). Although research has made some important contributions to support developments in many areas, the

relationship between research evidence and policies is rather weak. Black (2001) provides a summary of problematic areas that may be responsible for this gap: policy makers have goals other than maximising clinical effectiveness and that could be social or financial; research evidence may be dismissed as irrelevant if it comes from a different sector or speciality; there may be a lack of consensus about the research evidence because of its complexity, scientific controversy or different interpretations. In addition, policy makers may value other types of evidence such as personal experience, local information, and eminent colleagues' opinions (Trostle *et al.* 1999). Table 2.2 lists the reasons why research evidence has little influence on policy making.

Table 2.2 Research evidence and its influence on policy making

• Policy makers have goals other than clinical effectiveness (social, financial, strategic, development of service, terms and conditions of employees, electoral)
• Research evidence dismissed as irrelevant (from different sector or speciality, practice depends on tacit knowledge, not applicable locally)
• Lack of consensus about research evidence (complexity of evidence, scientific controversy, different interpretations)
• Other types of competing evidence (personal experience, local information, eminent colleagues' opinions)
• Social environment not conducive to policy change
• Poor quality of knowledge purveyors

In the area of cancer care, the UK has been one of the countries in Europe that has produced powerful policies. The Calman-Hine Report published in 1995 (Department of Health 1995) was the first British serious government policy on cancer, addressing the provision of all aspects of cancer care. Thereafter, the NHS Cancer Plan (Department of Health 2000a) followed retaining the main recommendations of the Calman-Hine Report and extending the scope of the policy by introducing themes above service delivery such as prevention and screening. The formation of these policies seems to have been influenced by both context and evidence in the area of cancer care. The policies implemented in Great Britain have been acknowledged by

WHO (2001) that cites United Kingdom as an example where cancer services are effectively organised.

In Greece, the Ministry of Health is charged with the responsibility of developing cancer care policies for the whole country. Since the early 1950s, consecutive governments have formatted policies against cancer. However, mainly due to financial restrictions most of the policies failed to be enacted. In 1983, as part of the NHS, an Oncology Council, composed only of doctors, was established to form part of the Central Health Council. This council advises the Minister of Health on matters relating to the service. Currently, this council meets two or three times a year and decides mainly on the distribution of the Hellenic Anti-cancer Society's funds raised. One of the contributions of this council was the attempt of creating a cancer data-base in 1987 (Dontas 1995b). It is notable that health policy making in Greece is highly context orientated. The Greek attitude is one of addressing problems once they arise with a disregard of evidence based solutions (Petridou *et al.* 1999). However, in the context of policy making the decision makers are political parties, the health professional associations and the trade unions. Healthcare users are hardly involved or informed.

Black (2001) concludes that there is a need to understand that sensible decisions while developing policies may not reflect scientific rationality as the context is important, especially with policies related to services. Communication of needs between researchers, policy makers and users needs to be improved. It is also acknowledged that healthcare developments have largely been led by policy makers, professionals and academics. It is not certain that they will have always addressed the processes of care and outcomes that are most important to citizens, consumers or patients (Thornton *et al.* 2003).

2.4.2 User Involvement in Healthcare

Over the past decades, users of healthcare services have become much more involved in the area of healthcare. The increased user participation is related to social and health issues in the 1950s and 1960s and the WHO's redefinition of health to include socio-political factors (Gray *et al.* 1995). There are several ways in which users and

the public can be involved in healthcare decisions. People might be involved in making decisions about their own treatment and care or in decisions about service priorities and changes to services (Small and Rhodes 2000, McIver and Brocklehurst 1999).

The rational for involving users in decision making are:

- The right that users have to be involved in decisions that will affect them;
- Being involved in decision making may have a therapeutic value;
- The desire to provide a service that is more responsive to the needs and wishes of users (Barnes and Wistow 1993, Hickey and Kipping 1998, Tritter *et al.* 2003).

A way of involving healthcare users, mainly in the evaluation of health services, is patient satisfaction surveys which is one method of obtaining users' feedback. Despite the increased focus on patient satisfaction, the concept has seldom been explicitly defined, therefore remains difficult to measure (Jackson *et al.* 2001). Edwards and Staniszewska (2000), after reviewing the results of research in the field of patients' satisfaction surveys, concluded that the main problem with satisfaction surveys is that they give little indication of a user's experience of care and what users would like to see improved. Williams and Grant (1998) also denote that any attempts to elicit service users' views have been mainly limited to 'hotel' facilities and waiting times, rather than more technical aspects of care. Other methods that have been employed to encourage wider public participation include citizens' juries, health panels and focus groups. However, these have failed to produce real change, concentrating more on consultation than active involvement (Evans *et al.* 2003). Sniszewska (2000) suggests that it would be better to use methodologies that may give voice to users and allow them some scope to lead agendas for change.

Furthermore, Maslin-Prothero (2003) suggests that user involvement in the area of healthcare should occur at all stages of a project, from planning, commissioning, researching, through to the dissemination and presentation phases. However, it is anticipated that in order for users to make a meaningful contribution, they need to be provided with education and training. Maslin-Porthero (2003) also suggests that healthcare professionals need users who can debate and challenge their assumptions in order to move on. Organisations now exist that aim to promote user involvement,

develop alliances and empower users in research (Consumers in NHS Research 2002). Involving users in research has been demonstrated by Thorton *et al.* (2003) where health care users were engaged at several stages of research (from setting the research questions to disseminating the results). The authors conclude that users' active participation is fundamental to effective research in the field of patient centred healthcare if future practice, policy and research are to change. It is clear that there are differences between passive approaches to user involvement that seek merely to collect information and active approaches that seek to provide an opportunity for users to directly influence decision making (Tritter *et al.* 2003).

The main debate over the issue of user involvement in decision making about healthcare policies, as many health professionals would suggest, is that users of health services are not knowledgeable enough to articulate realistically what they require of the healthcare system (Poulton 1999). There is also an argument that healthcare providers and healthcare users do not have the same ideas about service priorities. Fischer *et al.* (2002) in a research of 60 triads, involving a person with schizophrenia, his/her mental healthcare provider and a family member, have demonstrated that less than half of the participants agreed on service priorities. However, there are opposing views such as that of Calnan (1995) who suggests that users' interests are focused and are concerned with the care they receive from professionals and other sources of healthcare. Edwards (2000) also reports that users have increasingly expressed discontent and they are no longer prepared to be passive recipients. User groups are keen to develop opportunities for partnership to influence policy formation and plan appropriate services that reflect their perceived needs based on their experiences of the current services.

With regards the issue of user involvement in the development of healthcare services, the Department of Health (2000b) in UK has published directives suggesting that the involvement of local people, including users and carers, in considering local services, is critical to the development of services. In addition, it has been recommended that any research funded by the British Department of Health must involve healthcare users (NHS Executive Trent 2001).

In Greece, public debate on health issues is mainly between political parties, the health professional associations and the trade unions. Patients' associations have gradually started acquiring increased power. Among these associations, the most influential are those of kidney failure sufferers, thalassaemics and families of children with cancer (Petridou *et al.* 1999).

2.4.2.1 Healthcare users' involvement in cancer care planning

In the UK, user involvement in cancer care services is at a relatively advanced level in policy terms and has a high profile in health services policy (Department of Health 2001). In accordance with the principle that the development of cancer services should be patient-centred and should take account of patients', families' and carers' views, as well as those of professionals' involved in cancer care (Department of Health 2001), the British National Cancer Alliance (NCA 1996) conducted a study of 75 patients in 12 focus groups on their views relating to the care they received and asked for ways in which services could be improved. Another study by Reeve and Bullivent (1995) with cancer patients within an oncology directorate, facilitated the voicing of their needs at a one day workshop.

It is important to note that there is a lack of knowledge among healthcare users regarding the issue of user involvement. Evans *et al.* (2003) in their study of 36 cancer services users' views on the concept of user involvement revealed that there is a lack of structure on how user involvement can take place. A misunderstanding was also identified on how user involvement works as the majority of the participants believed that user involvement means patients and carers taking part in making decisions about their own care, which is only one aspect of user involvement (Evans *et al.* 2003).

Although a debate exists regarding the credibility of services planning and assessment by users and lay carers, there is a clear need for a synthesis of users', providers', and purchasers' views (Joule 1993). Users' views cannot be substituted by those of either purchasers or providers and there should be a redistribution of the emphasis given to each in the commissioning and monitoring of services so that users' views are given more credence than has been traditionally the case. Although there are barriers to

integrating users' views into the decision making process about health services, the benefits of doing so certainly justify the effort (Small and Rhodes 2000). WHO (2002) also supports that principles should focus on the needs of the people by ensuring their active involvement. Therefore services can be developed in ways that will be acceptable by both patients and professionals as beneficial to all concerned.

2.4.2.2 The carer's role in the cancer situation

Although people have been looking after and caring for others throughout history, the term 'carer' is a relatively recent term (Morris and Thomas 2001). It has been used rather loosely in health research to cover a wide range of situations usually involving the care of a person who is dependent and requires help with the activities of daily living (Soothill *et al.* 2001). The Birmingham Carers Association in its web site (www.birminghamcarers.org.uk) defines 'carer' as:

"a person who looks after someone who has a disability, illness, mental health problem or frailty due to age, and who is not in paid employment in that role".

This definition clearly excludes those who already have a recognised title such as nurses, doctors and other health professionals. It also excludes those who provide care and are paid for the work they do as part of their employment.

Informal carers are usually family members or neighbours and friends who provide physical and/or emotional support for people enabling them to function independently in the community and without whom additional statutory provision would be required (Bulmer 1987, Hancock and Jarvis 1994). Commonly, the role of carer is assumed to reside with or is adopted by an adult female family member, however, men and children can also undertake this role (Low *et al.* 1999).

In general, caring as an activity is located primarily within the family, where frequently it is considered to be a moral obligation (Bulmer 1987, Dearmun 1992). This often includes the expectation that families will care for those members who require additional support as a result of illness or disability. Many of these assumptions are embedded in public policy where concerns about undermining the role and function of the family within the social structure of society are frequently

expressed (Bulmer 1987). This policy context provides the background within which health professionals practice and through which family members or other neighbours and friends become defined as informal carers requiring support and education from healthcare practitioners to maintain their caring role. The processes, by which this support is negotiated within a contentious moral climate and the assumptions about the quality of caring relationships within the family, or between the patient and informal carer, remain problematic for many carers and for healthcare practitioners (Doty *et al.* 1998, Clarke 1999).

The carer concept has only been recently explored in the cancer literature. Prior to the 1980s carers in cancer were little remarked as providers of assistance to the patient, generally subsumed under the heading of 'family'. However, the question remains whether people who look after a cancer patient should be considered as carers. That was the case in a pilot study conducted by Morris and Thomas (2001) where the participants who were interviewed, queried whether they were infact carers, as the person they were with needed only little assistance with the activities of daily living. Thomas *et al.* (2002) suggest that there are times when the cancer patient's levels of impairment are relatively severe so that informal care work is required and other times when cancer patients are in remission and they do not experience illness symptoms. However, even the emotional support required by cancer patients and provided by people around them forms an element of caring. Thomas *et al.* (2002) conclude that it is appropriate to use the term 'carer' for people who undertake both physical care and psychological care for their spouse, partner, family friend, or close friend with cancer. In the current study, the term 'carer' is going to be used accordingly for those who look after a cancer patient.

Heron (1998) sees the term 'carer' from a political perspective and suggests that it is a term which unites carers into a group of people who have particular issues in common and who require some form of policy response. In Britain, the Carers National Association is the most prominent national organisation responsible for initiating and promoting the Carers Act, which was established to ensure that the needs of carers are addressed (Department of Health 1996). Carers are not only seen as supporters of cancer patients but as people who have psychosocial needs of their own. Research has started to focus on this area, with regards to carers unmet needs (Soothill *et al.*

2001), mainly in the area of palliative care (Rogers *et al.* 2000, Rhodes and Shaw 1999). More recently, the definition of consumers has expanded to include carers. In UK, the Department of Health's publication of The NHS Cancer Plan (Department of Health 2000a) suggests that the development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences, advocating consumer involvement in care processes.

The impact of caring on the lives of carers is well documented, in particular the inequities it creates for those who adopt this role and as a result forego other opportunities and the freedom to make choices that may be critical to their well-being (Doty *et al.* 1998). For example, in a survey of 3,031 carers belonging to the National Carers Association in the United Kingdom (UK), 70% reported spending at least 7 hours a day doing things for or with the person they cared for (Henwood 1998). From an economical perspective, it has been estimated that carers save the UK about £35 billion per year by the work they do (Heron 1998).

In Greece, a study by Iconomou *et al.* (2001) focused on the impact cancer has on carers of patients receiving radiation therapy. They reported that among the 65 carers in their study, women constituted 56.9% of the sample and that a large number of the carers in the study suffered high levels of anxiety and depression. According to the Hospital Anxiety and Depression Scale (HADS) results for the 65 participants in this study, 64.6% showed signs of anxiety and 63.1% were depressed. However, it must be noted that the HADS scale was developed to be used with hospitalized individuals and its validity and specificity is uncertain with non hospitalized individuals.

Furthermore, the carers' role in Greece is extended in the hospital settings. A Greek study by Bellou-Milona *et al.* (2001) revealed that of 150 patients' visitors in medical and surgical wards of general hospitals, 17.6% of the sample continually stayed close to their patients during their hospitalisation. The length of time visitors stayed next to the hospitalised patient was significantly influenced by the patients' wish to have their relatives next to them, showing the emotional and psychological link between these two groups. Seventy seven percent of the whole sample stayed close to their patients to care for their basic needs, which would be offered by nurses. Thus, a large

percentage of carers (80%) were women, in congruence with other countries where the majority of carers are women (Green 1988).

2.5 SUMMARY OF LITERATURE REVIEW

This chapter provided an extended review of the available literature on cancer care and services provided in Greece and the process of policy making in the area of cancer care.

Despite the efforts of consecutive Greek governments to establish an effective National Health Service, a large number of Greek people are dissatisfied with the services offered. With regards to cancer, it seems that Greece has low cancer incidence and mortality rates compared to other European countries, however the epidemiological data available are only estimates based on other countries similar to Greece. In addition, the limited available data on cancer mortality by the Greek state are under question due to inaccurate death certificate completion. Cancer services are provided in a variety of settings, however due to ineffective organisation, only few patients have access to effective cancer services. Home care services are under-developed and hospices do not exist, limiting the options available for terminally ill patients.

With regards to important areas of cancer care such as prevention, communication, psycho-social care, palliative care including pain management and education, the literature shows that in Greece there are considerable inadequacies. Primary prevention is not well developed and screening for breast and cervical cancer is not established on a national level. Palliative care, despite the lack of strong evidence, is regarded as the cornerstone of care for all cancer patients. However, in Greece, palliative care is not very well developed and pain management is not sufficient with a small number of Greek studies showing that a large number of cancer patients continue to experience pain. Communication between doctors and cancer patients remains a contentious issue in Greece and a large number of cancer patients remain unaware of their diagnosis. Psycho-social support is another area that needs attention as evidence shows that this support helps cancer patients.

In Greece, policy making in the area of healthcare is context orientated, addressing problems as soon as they arise. Decision making in the area of development and improvement of cancer services is characterized by little input from evidence and

limited participation form healthcare users. In recent years, carers have attracted much attention and it has been suggested that their views should also be taken into account in developing and improving services.

The current study will attempt to provide new evidence on:

- Cancer services that need to be developed;
- Areas of cancer care that need to be improved;
- Furthermore, a strategy for prioritising the above issues will be proposed.

The following chapter focuses on the design of the study and describes the methods involved in investigating the views of healthcare providers and users.

CHAPTER THREE

3. METHODS AND RESEARCH DESIGN

The aim of this study was to investigate healthcare providers' and healthcare users' views on the state of cancer services and cancer care in Greece. Samples from both parties involved were contacted to express their opinion on the important areas of cancer service and care provision through a process of prioritisation. The areas that required enhancement or development were established through a process of consensus building as a result of revisiting the identified areas and arriving at a unified judgement on their importance.

This process is featured in a methodology known as the 'Delphi technique'. Various modifications of this technique have been developed and used in the past to achieve consensus. In this chapter, the 'Delphi technique' will be described as the preferred method for this study, followed by the study design in which the research method chosen, sample, sample size, response rate are described. Finally, other methodological approaches that have been well documented in the literature together with a discussion of their unsuitability for the current study will be discussed.

3.1 THE DELPHI TECHNIQUE

The Delphi technique is a survey research method which aims to structure group opinion and discussion. The survey is a method of collecting data from a sample of the population of interest, usually by face to face interviews or questionnaires (Bowling 1997). Others can access the methods and procedures that are used by surveys so that the implementation and the overall design can be assessed. Survey designs are attractive to policy makers because of their accountability (Ong 1993).

The name 'Delphi' is derived from Greek mythology. Delphi, situated on the Pheaedriades cliffs, part of the mid-south of mainland Greece, is part of a wider

domain dedicated to the victorious Apollo who was the master of the city of Delphi. Prophecies about the future were made by the resident priestess (Charles-Picard 1969). Apollo 'spoke' through a medium guarded by priests at the Oracle of Delphi and predicted the future. Delphi is therefore closely associated with future predictions (Bowles 1999).

In the twentieth century, the appearance of the word 'Delphi' in research came from the use of the oracle's name for a project carried out in the early 1950s by the Rand Air Force Corporation in the USA. The aim of this project was to predict the outcome of Russian nuclear bomb strikes on the USA's munitions capability (Everett 1993). This study was named as 'project Delphi'. Since then, Delphi technique has been used in more than 1,000 published research projects and is described by researchers as highly motivating, novel and interesting (Bowles 1999).

The essence of the Delphi technique involves a series of intensive questionnaires to a panel of experts for the purpose of developing a consensus on specific questions and issues. The Delphi technique is therefore an iterative multi-stage process designed to combine opinion into group consensus (McKenna 1994). Delphi technique has been modified by various researchers and there are many differing forms in existence.

The 'classical Delphi' and the 'real time Delphi,' as illustrated by Jairath and Weinstein (1994) have been used to gather information and build consensus, with the 'real time Delphi' achieving it by any means of interactive networks. 'Classical Delphi' often uses a homogeneous group of experts who are not known to each other to give opinions on establishing facts in the future (Delbecq *et al.* 1986). Data are collected in a number of rounds and the results of preceding rounds are fed back until stability in responses among the experts has been reached through iteration (van Zolingen and Klaassen 2003). Respondents are informed of the other experts' views who participated in the first round and, in a number of rounds the experts are also given the opportunity to revise their opinion based on the feedback they receive from the researcher in the form of statistical summaries.

The 'policy Delphi' is another form of Delphi technique that follows the same steps as the 'classical Delphi'. However, the aim is to generate policy alternatives and the final round might involve the panel meeting to discuss divergent opinions (van Zolingen and Klaassen 2003). In addition, a heterogeneous panel is required for 'policy Delphi' in order to generate as many divergent opinions about the problem under consideration as possible with consensus not as a prerequisite (Turoff 2002). Finally, another form of Delphi technique, known as 'decision Delphi' is used for decision making which is following a process similar to that of the 'classical Delphi', however participants may be known to each other and consensus is desirable (van Zolingen and Klaassen 2003). All these forms of Delphi technique follow the same process for eliciting the participants' views through successive rounds of questionnaires. They only differ on the homogeneity of the participants' panels and the level of anonymity. Although Delphi technique is useful to researchers in health care (Zinn *et al.* 2001), only few researchers have used a uniform approach in its application resulting in doubts about its objectivity and scientific merit (Hasson *et al.* 2000).

The format of any Delphi study follows a series of rounds of data collection and analysis (Broomfield and Humphris 2001). As the Delphi technique is concerned with opinion, words and ideas, it could be suggested that it forms a qualitative method of research; however it is usually described as a quantitative tool (Tritter *et al.* 2003). Quantitative research aims at producing data that can be statistically analysed and whose results can be expressed numerically while qualitative research deals with information difficult to quantify such as subjective opinions and value judgements (Polit and Hungler 1999). Stewart (2001) suggests that Delphi technique illustrates the insufficiency of the terms 'qualitative' and 'quantitative' to describe a study. The terms 'qualitative' and 'quantitative' may refer to data, research and methods.

Delphi technique generates both qualitative and quantitative data. Stewart (2001) reports that in the first round, statements that represent the participants' views are collected (qualitative data), but in later rounds, in order to assess or gain consensus, the participants are asked to accept, reject, rank or rate these statements (quantitative data). In addition, although an interpretive analysis of qualitative data takes place in

the first stage, the researcher does not explore the meaning of the statements, but reduces them to fit under categories. The researcher employs a standardized and objective technique to interact with participants which places Delphi technique more in the quantitative paradigm (Stewart 2001).

With regards to the use of the terms 'qualitative' and 'quantitative', Stewart (2001) believes that they describe how the techniques and procedures used for data collection and analysis interact with one another. As Stewart (2001) suggests, it depends on the purpose of Delphi technique and whether it stems for an objective view of the phenomenon under investigation (quantitative paradigm) or a shared meaning developed from an interactive process (qualitative paradigm). All Delphi studies are concerned with opinion, words and ideas. However, these qualities do not make it the qualitative method as some authors have suggested (Broomfield and Humphris 2001). It seems therefore that Delphi studies borrow qualities from both the qualitative and the quantitative paradigms.

3.1.1 Characteristics of the Delphi Technique

There are a number of features characterising the classic Delphi procedure, such as the expert panel, anonymity, rounds of questionnaires and consensus which are also evident in most of the modified forms of Delphi technique. These features are presented in this section as well as other issues regarding the practical application of the Delphi technique.

3.1.1.1 Sampling and the use of experts

The success of a Delphi study rests on the combined expertise of the participants who make up the expert panel (Powell 2003). There are two controversial issues involved in this area: what qualifies a participant as an expert and the panel size. In most cases, Delphi technique does not rely on a random sample; rather it employs 'experts' as representatives of the target population (Hasson *et al.* 2000). By definition, each respondent is an expert in the area of interest.

There is controversial debate over the use of the term 'expert' and how to adequately identify a person as an expert (Hasson *et al.* 2000). Researchers have tried to address this issue in different ways. McKenna (1994) defined experts as a group of 'informed individuals'. Goodman (1987) described experts as 'specialists' in their field, and Green *et al.* (1999) as those who have knowledge about a specific subject. Goodman (1987) suggested that it is difficult to distinguish expert opinion from that of anyone else, so how an expert is defined is somewhat arbitrary. Furthermore, Bowles (1999) concludes that expertise is a valid construct but it is difficult to identify who possesses it. Most Delphi studies have relied on experts who have been chosen for their work and credibility in the area as the target population. For example, a panel in the clinical area may include expert clinicians, researchers with scientific expertise and patients who have expertise by virtue of having experienced the impact of a condition (Powell 2003). According to Kennedy (2004), the best approach is to describe the panellists fully so that judgements may be made about their credibility.

In terms of the appropriate number of participants in a Delphi study, surprisingly there is little agreement. An appraisal of several studies shows that the range of panel sizes varies considerably according to researcher preference. Reid's (1988) critique of the Delphi, for example, listed 13 published studies in health applications where the size of the panel varied from 10 to 1685. It is suggested that with a large number of participants, the reliability of a complex judgement increases (Powell 2003). However, there is very little evidence on the effect of the number of participants on the reliability or validity of the research outcome (Murphy *et al.* 1998). Few researchers have used large samples as the follow-up response rate decreases in inverse proportion to the size of the panel (Reid 1988). In addition, Hasson *et al.* (2000) suggest that the larger the sample size, the greater the generation of data, which in turn may influence the amount of data analysis to be undertaken. It is advised that the sample size and heterogeneity should depend upon the purpose of the study, the design selected and time frame for data collection (Keeney *et al.* 2001).

3.1.1.2 Anonymity

One of the benefits of the Delphi technique is that it provides anonymity for the participants (Bowles 1999). Anonymity secures an equal opportunity for each panel member to present and react to ideas unbiased by the identities of other participants (Goodman 1987). Anonymity also enables respondents to be open and truthful about their views on certain issues, without the influence of peer pressure or other extrinsic factors. However, complete anonymity may lead to a lack of accountability for the views expressed thus encouraging ill-considered judgements (Keeney *et al.* 2001). According to Goodman (1987), the instant unconsidered response is not likely to occur since the participants were recruited for their knowledge and willingness to participate.

Complete anonymity is not guaranteed when using this method, as the researcher knows the panel members and their responses. Keeney *et al.* (2001) report that in some Delphi studies, panel members do know each other, but they cannot attribute responses to any one member specifically. McKenna (1994) used the term 'quasi-anonymity' to indicate that respondents will be known to the researcher and even to one another. It should be noted that the concept of confidentiality is more applicable to that of anonymity in the Delphi studies where the researcher knows the respondents. Confidentiality refers to the legal or ethical duty to keep private and not disclose identifying or other significant information about the parties involved in a study (Von Kanel 1997). One of the main aims in Delphi studies is to keep private and limit access to the respondents' identities, but to facilitate respondents' communication through the questionnaires. In that case, the respondents' identities are not disclosed by the researcher to the rest of the panel, thus achieving confidentiality, and their judgments and opinions circulated through the questionnaires remain anonymous.

3.1.1.3 Delphi rounds

All forms of Delphi technique employ a number of rounds in which questionnaires are sent out and are used until consensus is reached (Beretta 1996). Round one is usually used to generate ideas and starts with an open-ended set of questions allowing panel

members freedom in their responses. Rounds two to four often take the form of structured questionnaires (Keeney *et al.* 2001). In each round, the summary of the results of the previous round is included and evaluated by the panel members. The number of rounds depends upon the time available and whether the researcher commenced the Delphi sequence with one broad question or with a list of questions or events. The process raises the question of how many rounds it takes to reach consensus. Keeney *et al.* (2001) report that the classical original Delphi used four rounds, however this has been modified by many to suit individual research aims and in some cases it has been shortened to three or two rounds (Beech 1999, Green *et al.* 1999). It is challenging to keep a high response rate within a Delphi study that has many rounds. If this is the case, the topic has to be of great interest to the panel members or they have to be rewarded in other ways.

3.1.1.4 Consensus

Consensus is one of the essential features of Delphi technique and the method of determining whether it has been reached is critical (Hardy *et al.* 2004). However, this remains a contentious issue in Delphi studies and numerous criteria appear in the literature. Setting a percentage level for inclusion of items as consensual appears to be a common interpretation; however, it is construed at different levels. Williams and Webb (1994) suggested that the criterion for judging consensus should be 100% agreement between participants. Alternatively, Salmond (1994) set the standard of consensus at 'very high priority' for those items that were rated as six or seven on a 7-point Likert type scale, by 70% of participants. Beech (1997) was less specific suggesting that consensus was implied by the results.

It is evident that when using the Delphi technique, the meaning of consensus is uncertain. In considering other Delphi studies, it is apparent that many researchers do not attempt to set a level for consensus prior to the study, and make a decision after the data have been analysed. Williams and Webb (1994) conclude that the concept of consensus is arbitrary and it is usually decided by the researcher, who allows the data to determine the level of panel agreement rather than specifying a suitable criterion prior to the inquiry.

3.1.2 Advantages and Disadvantages of the Delphi Technique

One of the main advantages of the Delphi technique is that it utilises a large number of opinions and avoids the drawbacks associated with committee process (Bond and Bond 1982). Responding to the Delphi gives the anonymity that cannot be achieved within a committee and provides an equal chance for each participant to present and react to ideas unbiased by the identities of other participants (Beretta 1996). In addition, the lack of interviewer bias and subsequently low costs resulting from no travelling to interview participants make the Delphi technique more advantageous than other methods. Delphi technique also provides the researcher with a large amount of data from diverse groups that would be unlikely to gather with many other methods (Kennedy 2004). Furthermore, content validity is an important concept when identifying knowledge in a specific area (Polit and Hungler 1999). Goodman (1986) proposed that the use of a panel of 'experts' increases the content validity of the Delphi as a tool for data collection.

On the contrary, Delphi technique has been criticised heavily for its scientific merit. Most of the criticism derives from the numerous modifications of the technique that have led to a lack of methodological rigour (French *et al.* 2002). In addition, it has been criticised in relation to reliability and validity (Keeney *et al.* 2001). It is prominent that there is no guarantee that the same results can be obtained if the same information was given to two or more panels (Beretta 1996). Goodman (1987) also states that the researcher can have no influence in any of the development stages of the survey, which could have implications for face validity.

Another area that has attracted considerable criticism within the Delphi technique is the issue of sampling and in particular the concept and definition of the 'expert' and the panel size (see chapter 3.1.1.1). Another disadvantage is that the Delphi technique may be a time consuming procedure. Delbecq *et al.* (1986) suggested a minimum of 45 days to allow questionnaires to be posted, returned, analysed and re-developed for the subsequent round.

Delphi technique, like any postal survey, is open to ethical considerations of truth and honesty. The researcher cannot be certain that the nominated individual is the person who completed the questionnaire, or whether it has been the focus of discussion with other individuals. It is also impossible to ascertain whether individuals respond with honesty or according to their perception of what the researcher expected. Another conundrum of Delphi technique is that it is difficult to recognise whether the increase in agreement between rounds is because the feedback supplied to participants has worked in a constructive way to help them refine their judgements, or whether these experts have just conformed to the majority view (Greatorex and Dexter 2000).

Furthermore, Delphi technique requires participants to be literal and skilled in writing as it involves written communication. This raises issues of representativeness as those who are illiterate or unable to communicate in the chosen language will be excluded from participating (Beretta 1996). This method is also exposed to biases both from the side of participants when they fail to send back replies contributing to sample bias (Polit and Hungler 1999) and the side of the researcher who may potentially introduce bias at all stages, from the design of the first round questionnaire to the content analysis of the results (Bowles 1999). The disadvantages described raise the question of generalisibility of the results. This issue is usually resolved by comparing the results of the Delphi study with the results of a randomised control study or other studies that are not known to the Delphi participants (Powell 2003). However, Mackway-Jones *et al.* (1999) whose Delphi study concerned major incident planning for child casualties were confident in the use of their findings by suggesting that they may be applied generally. The following table (Table 3.1) provides a summary of the advantages and disadvantages of the Delphi technique:

Table 3.1 Summary of the advantages and disadvantages of the Delphi technique

Advantages	Disadvantages
Can explore a range of questions	Needs relatively simple statements
Easy to include large numbers	Participants do not meet so does not allow discussion
Can include people from a wide range of backgrounds	Participants must be able to read and write
Draws on a wide range of expertise	Outcomes limited by quality of input
Democratic	Minority views get lost

The Delphi technique is dependent on the experiential knowledge of its expert panel (Powell 2003). In this regard, it should not be viewed as a scientific method for creating new knowledge, but rather as a process for making the best use of available information, be that scientific data or the collective wisdom of participants (Black *et al.* 1999). Delphi technique shares common features with other consensus methods, such as nominal group technique. However no other technique enables open-ended questioning, attitudinal measurement and controlled anonymous feedback, concepts imbedded both in the quantitative and the qualitative paradigms (Bowles 1999). In addition, Delphi technique provides an alternate approach which maximises the benefits of surveys and other consultative processes while minimising their limitations (Jairath and Weinstein 1994).

3.1.3 Application of the Delphi Technique in Healthcare Research

To investigate the extent of use of the Delphi technique in health issues, Bowles (1999) searched CINAHL and Medline databases for a period of almost 20 years (between 1981 and 1998). In 292 database entries, the word 'Delphi' or 'Delphi technique' appeared. Of these, 288 were descriptions of the technique and 187 addressed nursing issues. A further search on CINAHL for the years 1999 to 2003 revealed 279 entries where the word 'Delphi' or 'Delphi technique' appeared. Of these entries, only 91 addressed nursing issues.

The Delphi technique has been utilised by many nurse researchers in a wide variety of studies. Crotty (1993) has used it in curriculum development, Williams and Webb (1994) and Kirk *et al.* (1996) in healthcare education. Lindeman (1975), Bond and Bond (1982) and Goodman (1986) used Delphi technique in identifying priorities for nursing research. Salmond (1994) used the same technique in identifying research priorities in orthopaedic nursing and Schmidt *et al.* (1997) in identifying research priorities in paediatric nursing. Reid (1988) used Delphi technique to evaluate the clinical nursing environment, Procter and Hunt (1994) to develop dependency criteria for the assessment of nursing workload and staffing numbers, and Beech (1999) into the management of changes.

In recent years, Delphi techniques have also been used in the area of health services development by examining health professionals' and service users' views. For example, Beech (1997) used a Delphi survey of multi-disciplinary clinical staff to examine the likely developments of the community mental health centres in North Staffordshire. In addition, Cangialose *et al.* (2000) convened a panel representing various stakeholders in the healthcare delivery and oncology services marketplace to develop specific criteria for healthcare purchasers to consider when evaluating the structures and processes of health plans in USA. With regard to users' views, an Australian study has been conducted by Lowe *et al.* (1995), which through the use of a Delphi process, a questionnaire was developed to investigate community knowledge and attitudes regarding primary prevention of bowel cancer.

3.1.4 The Suitability of Delphi Technique for this Study

The main features of the Delphi technique proved to be appropriate for this study of healthcare providers' and healthcare users' views on the development of cancer services in Greece. First, it is well established that there is a general dissatisfaction with healthcare in Greece (Komninou 2000), however there is limited research on what could be done to improve the situation. Authors suggest using a Delphi technique in areas where there has been little previous work (Mead and Moseley 2001), which was the case in the current study. Second, authors suggest that Delphi is an effective method in the policy-making arena where issues need to be provided and

prioritised (Hasson *et al.* 2000). It was the intention of the researcher not only to investigate the views from these two groups, but also to prioritise them.

Healthcare providers and healthcare users would form the panel of experts. Healthcare providers are in a position to know what the health system is providing and whether any changes should be made to further improve the system. Cancer patients and carers are users of health services and they can contribute in the generation of suggestions about the improvement of cancer services in Greece. The participants would not meet face to face, maintaining their anonymity, and the researcher would only know them. That would enable the freedom in expressing their ideas. These could then be considered solely on their merits rather than on the basis of the articulateness and status of the person who suggested them. The participants could also be offered some feedback over the group's opinion. By using rules later in the study, consensus could be established for the prioritised suggestions.

In this research, a graphical representation of the classical 'Delphi technique' has been constructed in the form of a question mark as a starting point in any Delphi study (Figure 3.1). The sequence of events and actions that are to take place during the application of the Delphi technique are denoted on the question mark in order of their appearance. This pictorial representation has been introduced in this thesis providing a concise summary of the research process. Furthermore, it does not only simplify the presented ideas in a logical sequence and manner, but also allows a simple comparison of some other Delphi techniques to be made. It will also make the modification and extension of the Delphi technique, as proposed for this study, simple to observe and explain in the following sections.

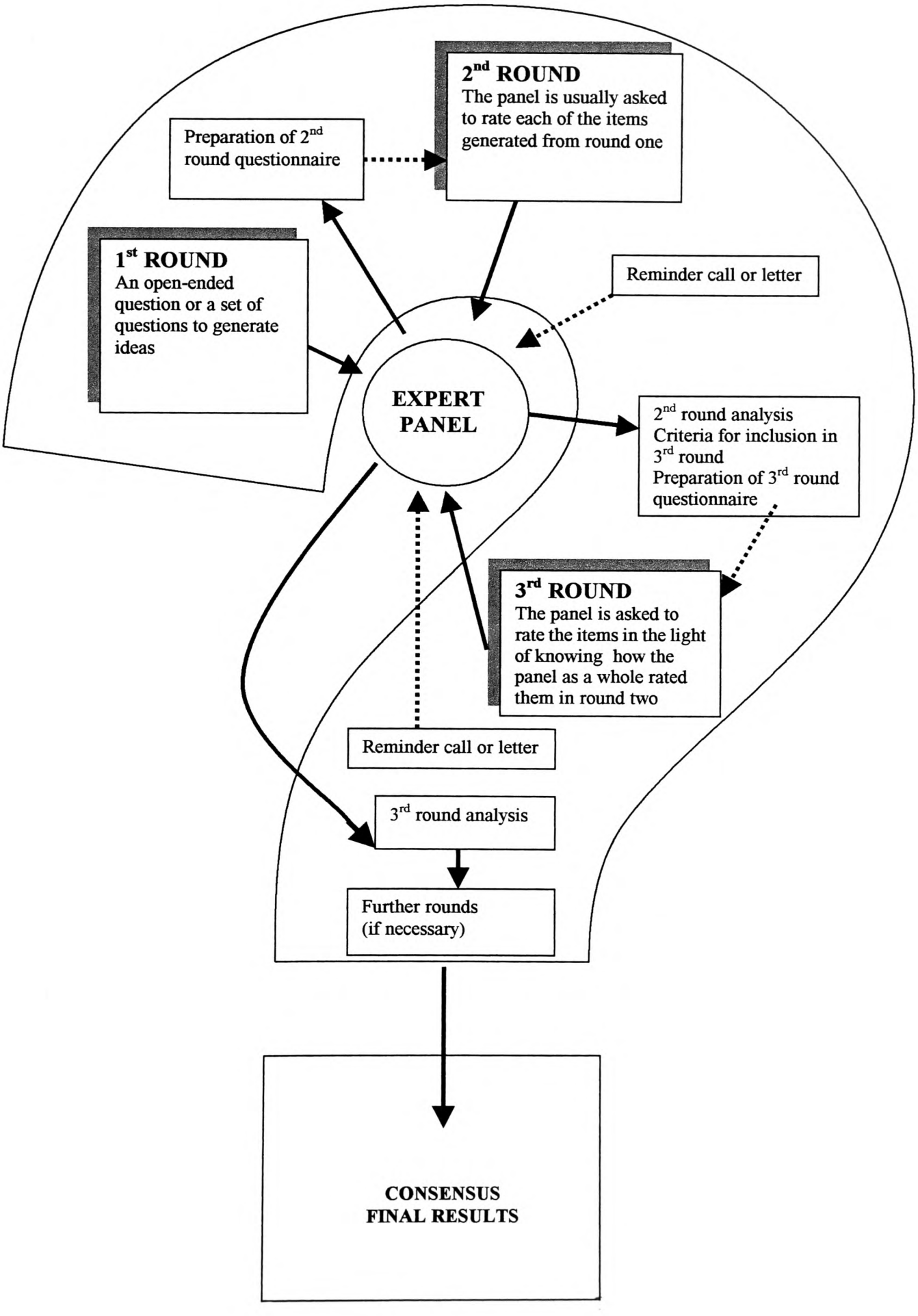


Figure 3.1 The flow chart of a classical Delphi study

3.2 REASONING FOR TWO DELPHI STUDIES

In this study, the method involved the use of two Delphi studies, one with health professionals in cancer care (healthcare providers) and one with cancer patients and carers of their patients (healthcare users).

The aim of the study was to investigate people's views on the development of cancer services and cancer care in Greece through their prioritisation. It was considered appropriate to collect data from healthcare providers who are in contact with cancer patients and healthcare users. Some of the existing studies on similar issues have focused only on healthcare providers' views based on the British White Paper 'The New NHS: Modern and Dependable' (Department of Health 1998) which has given health professionals an important role as patient advocates and has suggested that professionals are best placed to articulate patients' needs. The nurses' role as advocates of their patients has also been extensively discussed in papers (Mallik and Rafferty 2000, Wheeler 2000). However, the consumerism approach and other directives have also suggested that patients' and carers' views should be taken into account in the development of cancer services (Department of Health 2000a).

In this study, the opinions of both healthcare providers and healthcare users were considered important. It is acknowledged that the diversity of expert panel membership may lead to better performance as this may allow for the consideration of different perspectives and a wider range of alternatives (Powell 2003). However, it was anticipated that because of the diversity of the opinions that would be created, it would be difficult to reach consensus on the prioritised suggestions by both groups. It was also thought that the recruitment of the healthcare users' sample would be more time consuming and that this panel would need more time to complete the questionnaires. For this reason, and in order not to delay the process of the study, two separate Delphi studies were conducted, one with healthcare providers and another with healthcare users. Furthermore, the use of two samples to examine the same issues from two different perspectives would enable a comparison to be made between the findings obtained from two panels (Kennedy 2004).

3.3 ETHICAL CONSIDERATIONS IN CONDUCTING THE TWO DELPHI STUDIES

Tschudin (2001) reports that different countries within Europe follow their own practices and customs regarding the approval of research projects by ethical committees. After investigating the role of ethical committees in Sweden, Germany, France, Switzerland, the Netherlands and Italy, Tschudin (2001) concluded that it was only in UK that ethics committees were first approached for approval of any research activity.

Prior to the start of the current project, the Ethics Committee of the University of Glamorgan was approached and the project was approved (Appendix 2). In Greece there is no ethical committee in any of the Health Authorities. For this reason, there was no way that ethical approval for this research at the level of Health Authorities could be sought. However, healthcare providers were asked whether they wanted to participate in the study.

When research is conducted in a hospital in Greece to involve patients, the research proposal is usually reviewed by the hospital's scientific committee and permission is granted for its administration based on their decision. This is a prerequisite of any experimental research design including the testing of new medicine or a new treatment for patients. In the case of experimental research, patients are protected by the Greek law (Merakou *et al.* 2001).

None of the four recruitment hospitals in Athens (two general and two oncology hospitals) required special procedures regarding the conducting of this type of research (Delphi technique, non-experimental research). The Nursing Directors of the four hospitals were approached by the researcher and the aims of the study were explained. Special consideration was given to the fact that a large number of patients in Greece are not aware of their diagnosis (Mystakidou *et al.* 1999). It was agreed that the researcher would contact the nurse in charge of every ward caring for cancer patients and ask which patients knew their diagnosis. The researcher would then approach the patient or the carer and explain the aim of the study and ask their

consent to participate. After agreeing on these measures, all Nursing Directors gave permission for the research to take place.

One of the main characteristics of Delphi surveys is anonymity (Hasson *et al.* 2001). However, complete anonymity is not guaranteed when using this method, as it is likely that the researcher will know the panel members and their responses. For this study, the healthcare providers and healthcare users were only known to the researcher and not to one another. Participants were assured that their names would not be disclosed to the rest of the panel, thus offering participants' confidentiality on their identities.

3.4 THE DELPHI STUDY OF HEALTHCARE PROVIDERS

3.4.1 Recruiting the Expert Panel

As stated earlier (chapter 3.1.1.1), the Delphi technique hardly uses a random sample, rather it employs 'experts' as representatives of the target population. Representativeness is assessed on the qualities of the expert panel rather than its numbers (Powell 2003). The composition of the expert panel is crucial to the outcome of the entire undertaking and is only second in importance to the framing of the question(s) of round one (Mead 1993). In the face of contradictory opinions on the concept of 'expert' and who possesses it (Bowles 1999), a decision had to be made. Mead (1993) suggests that the best way to overcome the problem of defining the experts is to draw well defined inclusion criteria. An effort was made to set up certain criteria for participants to be included in this study.

The following inclusion criteria were established and in order for participants to be included in the panel, they had to meet at least one criterion from the following list:

- Doctor working in an oncology ward or Health Centre;
- Nurse working in an oncology ward or Health Centre;
- Doctor with research experience in cancer;
- Nurse with research experience in cancer ;
- Doctor regarded by peers as being an expert in cancer care;
- Nurse regarded by peers as being an expert in cancer care;
- Social worker regarded by peers as being an expert in cancer care;
- Health professional who is a member of a support group for cancer patients;

A combination of purposive and network sampling was used to recruit the sample that had to meet at least one of the established criteria. Norwood (2000) suggests that in purposive sampling, the knowledge of a population is used by the researcher to select the elements that will constitute the study sample. In network sampling, often called snowball sampling, initial sample members are asked to

identify and recommend others who meet the eligibility criteria into the study (Norwood 2000). Polit and Hungler (1999) suggest that network sampling is likely to be used when the research population consists of people who might be difficult to identify. However, in the current study, the advantage of using network sampling was that experts in cancer care, rather than the researcher, identified potential participants who were acknowledged for their expertise in the area of oncology, reducing the possible bias of the researcher only identifying the participants. By using both sampling techniques, a database comprising 30 experts was obtained. The expert panel's profile is described in table 3.2:

Table 3.2 The expert panel's profile for the study with the healthcare providers

Participants	No
Nurses working in Oncology Hospitals	4
Doctors working in Oncology Hospital	5
Nurses working in Home Care	2
Doctors working in Home Care	1
Nurses working in Health Centres	4
Doctors working in Health Centres	3
Cancer nursing researchers	3
Medical researchers	1
Social workers	3
Support members	4
Total	**30**

Once established, the panel consisted of a wide range of healthcare professionals forming mainly three groups: doctors, nurses and other health professionals. Some of the participants met more than one of the inclusion criteria. Two of the cancer patients' support members were nurses working in cancer hospitals and the medical researcher was a doctor in a cancer hospital. Two nurse researchers were working in hospitals and the third was a lecturer in a School of Nursing. Two nurses were also members of the board of directors of the Hellenic National Nurses Association. One

was a member of the Oncology Counsil of the KESY (Central Health Committee). Four fifth of the participating nurses were senior with many years of experience in cancer care, while doctors were representative of all levels. Twenty five members of the panel were from the greater geographical area of Athens where most of the expertise is concentrated. Two doctors, two nurses and a psychologist working in oncology wards were from other areas of Greece representing each of the three large groups of the healthcare providers' panel.

With regards to the number of participants in this study, it must be noted that there is not an ideal panel size (Bowles 1999). However, Keeney *et al.* (2001) suggest that the panel size and its heterogeneity should depend on the purpose of the study, design selected and time frame for data collection. It was anticipated that 30 participants would form a heterogeneous group for this study, and that the amount of data they would generate would be manageable and would not pose analysis difficulties in the first round where a qualitative approach was to be employed.

3.4.1.1 Telephone recruitment

For this Delphi study, subjects were telephoned at their workplace. The aim of the study was explained and they were asked if they agreed to participate. All 30 subjects agreed to participate. After their agreement, they received a letter with more information about the study (Appendix 2), a leaflet giving information about Delphi technique (Appendix 3), and the question of the first round of the Delphi (Appendix 4). A pre paid envelope bearing the university logo was enclosed with the questionnaire. In the accompanying letter it was stated that the return of the questionnaire implied their consent to participate and that was granted.

3.4.2 Delphi Questionnaires

Data collection of the healthcare providers' views consisted of three rounds. The purpose of the initial iteration was to identify the areas of cancer care and the cancer services that needed to be developed or improved in Greece. Responses to the first questionnaire were analysed and a second questionnaire was developed from these initial responses. The healthcare providers were asked in this second questionnaire to

rate the priority of each of the issues raised in round one. These ratings were collated, and the consensual highest-rated responses were then fed back to the panel via a third questionnaire which asked respondents to rank them in order. This process is described in detail in the following sections.

3.4.2.1 Delphi 1st round

Round one of the classical Delphi starts with an open-ended question or a set of questions, allowing panel members freedom in their responses (Bowles 1999). An important issue in round one is the phrasing of the question or the questions. Delbecq *et al.* (1986) suggest that the development of the question in round one is the key to an effective Delphi process. By contrast, participants who do not understand the initial broad question may answer inappropriately or become frustrated with the questionnaire and lose interest. Keeney *et al.* (2001) also suggest that if the questions are not well phrased, the reliability and validity of the data may be threatened. After much deliberation on the question of the first round questionnaire and the advice of an expert in conducting Delphi studies, the question developed for this study was:

> *"In your opinion, which cancer services and which areas in cancer care, need to be developed or improved in Greece?".*

The terms 'cancer services' and 'cancer care' may appear too general. However, they were consciously selected and deliberately not defined in this round. They were simply intended to act as a stimulus to enable respondents to indicate what sort of items they would include as 'cancer care' and propose any 'cancer services'. As cancer services already exist and cancer care is offered, the words development and improvement were used so that participants could express any need in these areas.

The question was first developed in English. The question of the study was going to be applied to Greek speaking subjects, so it had to be translated in Greek with the integrity of the question ensured. This task was performed by the researcher who translated the question in Greek and three bilingual individuals who back translated it in English. Back translation by a number of bilingual subjects is the recommended procedure in the literature (Brislin 1970). As a result, the integrity of the question was

maintained. The Greek question was then piloted on eight Greek nurses. These nurses had experience of caring for cancer patients either in general or cancer hospitals. The responses received from the pilot group indicated that the Greek wording of the question did in fact elicit the information the researcher wanted to gather.

The number of items generated by one question can be extremely large, especially if the researcher chooses an all inclusive approach. For this reason, many researchers tend to limit the number of opinions the participants can contribute (Mead and Moseley 2001). Researchers who adopt an all inclusive approach usually end up with a long questionnaire for round two. Being all inclusive can be off putting for panel members participating and can become very difficult to sustain (Green *et al* 1999). Schmidt (1997) suggests that participants should be asked for at least six opinions, as several participants are likely to raise the same issue using different terms.

It was decided that a restricted response format in round one would be adopted. The participants in this study were asked to report no more than five statements, aiming for the quality of the suggestions rather than their quantity. By limiting the number of suggestions to a small number, it is possible to potentially lose useful information, however the respondents' attention is focused on the importance of the suggested items (Mead and Moseley 2001).

3.4.2.2 Preparation for the 2nd round questionnaire

The statements received from round one were in Greek language. As English speaking individuals would do the analysis of the data, the statements had to be translated to English. Translation of previously developed instruments has attracted the attention of researchers as many instruments validated in English language have been translated and used in a second language. Brislin (1970) has suggested back translation as the preferred procedure to establish the equivalence of its back translation. This procedure involves a translator blind to the original questionnaire who translates the questions back into the original language. The back translated

questionnaire is then compared with the original and any discrepancies are examined and resolved (Del Greco *et al.* 1987).

Chang *et al.* (1999) suggest that the process of translating concepts developed in one culture for use in another is fraught with problems of semantics. The challenge is even bigger when qualitative data requires translation for the purpose of data analysis. Twinn (1997) has studied the influence of translation on the reliability and validity of the findings of a qualitative research study. No significant differences were identified in the major categories generated from the original and the translated data. However, the complexity of managing data when there were no equivalent words in the target language and the influence of the grammatical style on the analysis were acknowledged (Twinn 1997).

The statements generated in round one were translated by the researcher from Greek to English. Two bilingual individuals back translated the statements. The translation did not pose any difficulties as most of the statements were simply stated, the translators were familiar with the issues raised and there were no words without translation equivalency. Finally in all items, the back translation was either identical or the integrity of the statement had remained. The most important consideration when translating data from one language to another is for both versions to convey the same information rather than maintaining the linguistic structure (Chang *et al.* 1999).

The conventional method for recording and analysing the statements generated in round one involves transcribing each statement that was obtained onto a separate card together with an identification code for the respondent (Mead and Moseley 2001). The same procedure was followed for the translated statements generated in the first round of this study electronically. The suggestions obtained from round one were transcribed using the APPROACH software programme by LOTUS Smart Suite. APPROACH is a database handling software. All items were given a unique number which linked the statement with the respondent. This type of computer programmes speeds up the manual process and permits the exploration of wide variety of different forms of coding and sorting of the data (Mead and Moseley 2001).

Data collected from round one was of a qualitative nature and a content analysis approach was used to identify themes. The purpose of identifying and defining themes is to provide a means of describing the phenomenon under investigation and increase understanding (Cavanagh 1997). Hasson *et al.* (2000) have also suggested that data collected from this initial stage should be analysed by grouping similar items together, making the second round questionnaire easier to be completed by the respondents. The statements may then be grouped under these themes.

The literature is not very informative about this stage of analysis. In most cases one researcher or two perform the content analysis of the items that are provided by the participating members and create themes under which the items are presented in the second round. This critical process can therefore be influenced by the researcher's subjective judgment biasing the findings and possibly driving the remaining research steps (Bowles 1999). For example, if a statement's content is not very clear, it is considered by the researcher to fall into a certain category and is presented under that category in the second round questionnaire. The respondent then, who is not in favor of that category might not rate it high, whereas the same statement under another category might have been rated higher. Furthermore, the purpose of content analysis in the first round of Delphi technique is not gaining depth of understanding of the statements provided (Stewart 2001), but to create categories under which the statements will be presented in the following rounds. For this reason, an objective relationship with the data is required and this objectivity can be acquired by involving more people in the analysis of the data.

In the current study, this major weakness has been addressed by reducing the researcher's subjective influence on the research outcome. This was achieved by introducing a panel of experts to perform the content analysis, hence replacing the subjectivity component by objectivity. It was anticipated that the themes created by a panel of experts would be more valid and objective. Another added component in this thesis is the ranking in order of the consensual items in the final round of the Delphi technique. Henceforth, we refer to this new Delphi technique as Q-Delphi as it is presented in the shape of a question mark.

3.4.2.3 Q-Delphi 2nd round

The questionnaire used in the second iteration included the statements generated by the panel from the first round under the categories created after the content analysis (Appendix 5). The 30 panel members were asked to rate each statement on a seven point Likert type scale, from one, meaning very low priority, to seven, meaning very high priority.

Likert type scales have been used widely in Delphi studies for prioritisation. However, in some studies, the process of prioritisation has been rather indirect. In some studies for example, researchers have asked how many people can benefit from a policy with a seven point Likert type scale for the response, or offer a magnitude ratio scale (Mead and Moseley 2001). In this study, a seven point Likert type scale was used, because the questionnaire was very lengthy and the researcher wanted to avoid asking complicated questions. Another reason was that the researcher wanted to focus specifically on the prioritisation. It was decided to use seven points for the Likert type scale given that a smaller number would give little scope for fine judgements (Mead and Moseley 2001). Indeed, more points would exceed human capacity for holding items in short-term memory (Baddeley 1994).

The questionnaire for round two was sent to all the members of the panel. On the first page of the questionnaire completion instructions were included. As the statements were presented under categories, emphasis was given to the participants to rate each statement separately and not the categorisation. An accompanying letter was included thanking all the participants who responded in round one and they were requested to return the completed second round questionnaire in the pre-paid envelope (Appendix 6). After three weeks, a reminder call was made to the participants who had not returned the questionnaires. On the sixth week, the second round was assumed to be complete as no further questionnaires had arrived.

The data from round two were analysed using the Statistical Package for Social Sciences (SPSS). The scale upon which participants expressed their opinion was an ordinal scale, however many researchers assume it to be an interval scale that

allows for descriptive statistics such as the means and standard deviations to be calculated for item scores on each round (Greatorex and Dexter 2000). The measures of central tendency (means, medians and mode) and levels of dispersion (standard deviation and the inter-quartile range) were computed for each of the items derived from round one question. Correlation coefficients were computed for the mean ratings between the groups of health professionals in order to establish if there was any association between the groups' ratings. Pearson's product -moment correlation coefficient was used as the data were of an interval format (Norwood 2000). A positive correlation would mean that high ratings from one group tend to be associated with high ratings from the other group. A strong positive correlation would also show a degree of agreement between the groups' decisions.

3.4.2.3.1 The choice of mean scores as indicators of high prioritised items

In the literature, different approaches are reported on the analysis of the 2nd round of a Delphi study which involves the setting of priorities among participants. Kreber (2002) for example has used the median, which is the point above and below which 50% of the participants fall, as an indication of importance. On the contrary, Broomfield and Humphris (2001) in their study have used the mean to provide an indication of importance. If the frequency distribution is symmetric then the mean, median and mode provide the same information. But in general, the median as a central tendency measure has advantages when there are a few extremely low or extremely high values (Kviz and Astin Knalf 1980). In the second round of this Delphi study a large number of responses were marked as six (high priority) or seven (very high priority) on the seven point Likert type scale and there were no extremities on the ratings. For this reason in this study, the mean score was chosen as a measure of central tendency to distinguish the higher prioritised items.

3.4.2.3.2 Setting criteria for consensus

Consensus is a fundamental element of Delphi studies; however it is poorly explained in studies which use the Delphi technique (see chapter 4.1.1.4). Many researchers set a level for consensus after the data have been analysed (Williams and Webb 1994). The data received from round two suggested that there was agreement among the panel, as more than half of the statements had a high mean score. At this stage criteria were set for consensus. A cutting point was set so that high prioritised statements over that point would be considered consensual. Statements with a mean rating score of six and above and not rated below four on the seven point Likert type scale were considered consensual for the purposes of this study.

3.4.2.4 Q-Delphi 3rd round

The third round questionnaire evolved from round two containing the statements that were consensual among the participants. Panel members were asked to rank the statements in order within different categories. This modification as well will be part of the Q-Delphi technique in the future. Grouping the statements in categories and asking the participants to rank them in order within each category was considered better as the participants would not have to make considerable comparisons. Even with 20 statements to be compared and ranked, the rater has to make 190 comparisons (Mead and Mosley 2001). The ranking in order of consensual statements among the panel is not a new approach in Delphi technique and it has also been used in Pelletier *et al.*'s (1997) Delphi study on the cardiac nurse's role.

All the participants involved in the study received the third round questionnaire with instructions on how to complete it on the first page (Appendix 7). An accompanying letter thanking those participants who completed the round two questionnaire was also included. A summary of the second round results was also presented in the letter, inviting those who did not respond in round two to complete the third round questionnaire (Appendix 8). After three weeks, a reminder call was made to those

who had not returned the questionnaire. At the end of six weeks, the third round was assumed complete as no further questionnaires were arriving.

In round three, the sum of all ranks assigned to an item was computed within each thematic group using SPSS. The Kruskal-Wallis test, a non-parametric test for data of an ordinal nature, was used to investigate if there were any significant differences between the three groups of the participants. The Kendall coefficient of concordance (Kendall's W), a non-parametric test for data of an ordinal nature, was also used to investigate if there was any significant agreement on the rankings among the participants from each of the groups of doctors, nurses and others.

The following diagram (Figure 3.2) shows the steps of the modified Delphi technique, called Q-Delphi, as it was used in this study with the healthcare providers. It is in the form of a question mark in the same way the classical Delphi process was presented in figure 3.1. The added dimension in this procedure was the use of an expert panel in round one to create the themes as opposed to other Delphi studies where the researcher alone or two researchers undertake this task. Furthermore, the participants in the final round were asked to rank the statements rather than rate them. The added dimensions are highlighted.

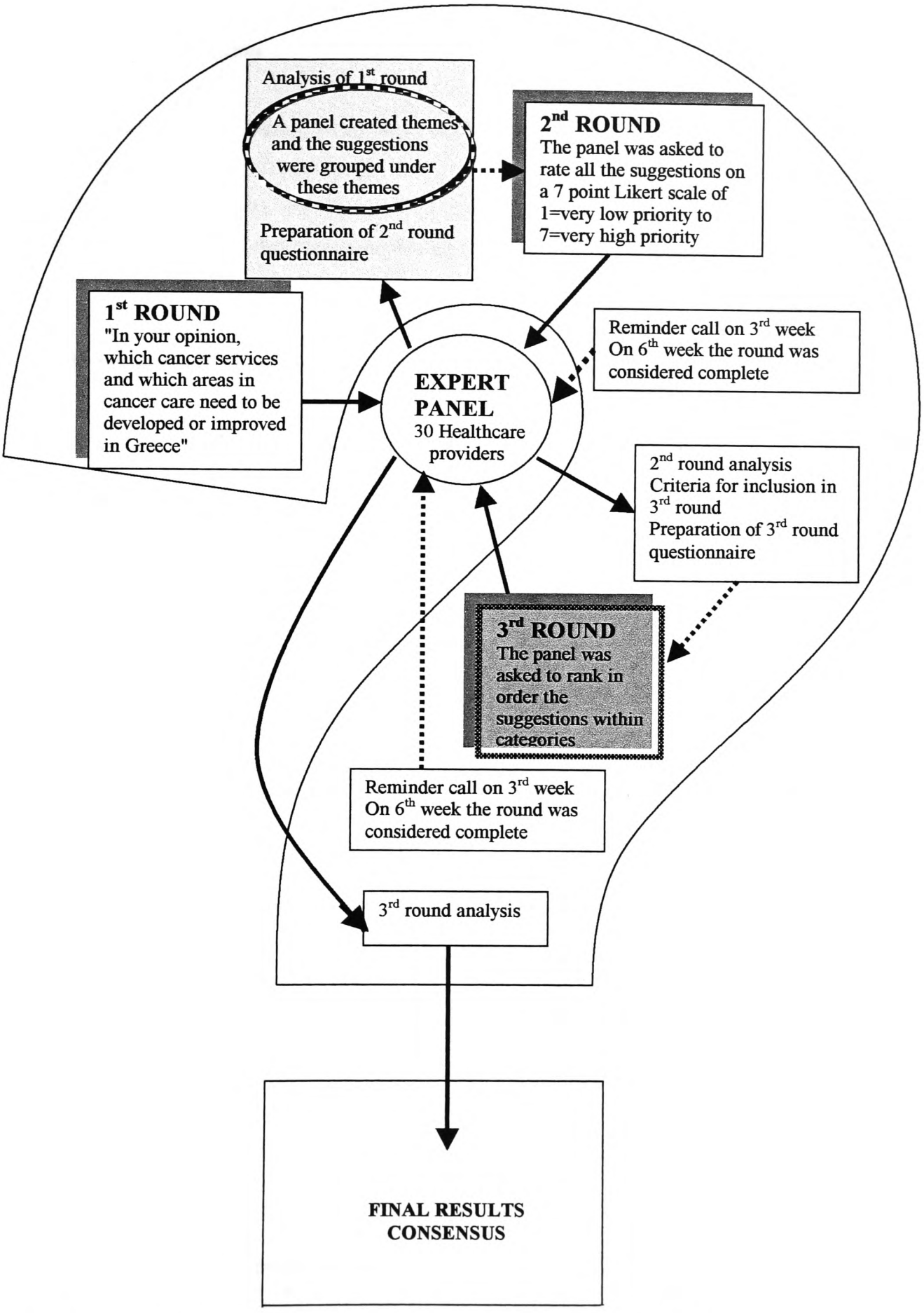


Figure 3.2 The flow chart of the healthcare providers' Q-Delphi study

3.4.3 Sample Attrition

One of the problems reported with Delphi studies is that after the first round, panel members may fail to respond (Bowles 1999). This may contribute to sample bias (Polit and Hungler 1999). Sumsion (1998) has suggested a response rate of 70% for each round, in order to maximise sample representation. The response rates for each round are presented in table 3.3:

Table 3.3 Response rate for each round of the healthcare providers' study

Rounds	No of participants	%
1st Round	30	100
2nd Round	23	77
3rd Round	26	86.7

It is possible that the researcher's personal contact at the beginning and during the study with the reminder calls, may have contributed to the successful response rates. Yet, even a high response rate cannot provide confidence about the non-responders. Although it is generally established that the larger the non-response, the greater the chance of bias, it is possible that even with a high response rate, a small sub-group may have evaded the survey (Lin and Kelly 1995).

There are several reasons for sample attrition (Health 1995 cited by Coll 2001):

- Respondents may move during the study and cannot be traced;
  In the current study this problem did not occur as the participants provided all the appropriate information at their first contact with the researcher. It was easy to trace the participants even if they had moved during the study, which did not happen for any of the participants.

- Elderly and infirm respondents may drop out due to ill-health or even death;

This did not prove to be a problem as the participants were essentially 'healthy'.

- Respondents may lose interest in the study;
  In some cases, respondents who completed round one and failed to send back the questionnaire of round two, complained that the questionnaire was very long and did not have enough time to complete it.

- Respondents may drop out because they are concerned about confidentiality and lack of privacy;
  This was not a problem with this study as all the respondents received information about Delphi technique with the first questionnaire and they were reassured about the issues of confidentiality and anonymity.

3.5 THE Q-DELPHI STUDY OF HEALTHCARE USERS

3.5.1 Recruiting the Expert Panel

In investigating healthcare users' perspectives on cancer care and cancer services development in Greece, it was decided to form a panel including both cancer patients and carers. The possibility of random sampling was considered in the recruitment of the sample for this Delphi study. However, in Greece there are no cancer registries so that a probability sampling technique could not be employed. As a result, and in order to have a random sample, information about the cancer patients registered in each hospital in Greece would have to be collected by the researcher. This procedure would pose economic and time constraints and probability sampling was considered unrealistic and impractical. Therefore, a similar procedure to that of the healthcare providers was adopted. Inclusion criteria were established and panel member participants had to meet at least one criterion from the list below:

- Cancer patient treated in an oncology hospital;
- Cancer patient treated in a general hospital;
- Carer of a cancer patient treated in an oncology hospital;
- Carer of a cancer patient treated in a general hospital;

For the cancer patients, it was necessary to have undergone the initial stage of cancer diagnosis and have received treatment (surgical, chemotherapy, radiotherapy) at least once recently. They also had to be able to complete a rather lengthy questionnaire. For the carers, the only requirement was that they had cared for a cancer patient at some stage of their cancer recently.

A convenience sampling approach was used to recruit the healthcare users to the sample. Norwood (2000) suggests that a convenience sample comprises the most conveniently available elements that meet the established criteria. Despite the critique on convenience sampling on grounds that it does not create representative samples, it was the best available approach for this study. The fact that many patients do not

know they have cancer also posed recruitment difficulties. However, an effort was made to use convenience sampling with care and to avoid any biases in selecting the panel members. Norwood (2000) suggests that convenience sampling would be acceptable if it is used with reasonable care and strengthened by making eligibility criteria more restrictive.

Both cancer patients and carers were approached in two general and two oncology hospitals in the area of Athens, aiming at recruiting a sample that would have a recent experience of cancer care. The aim of the study was explained and they were asked if they agreed to participate. If one agreed to participate, the researcher supplied the participant with an envelope containing a letter with more information about the study (Appendix 9), a leaflet giving information about Delphi technique (Appendix 10), and the question for the first round (Appendix 4). A free post envelope was also enclosed. The leaflet about the Delphi technique was specifically worded differently from that given to the healthcare providers as it was considered that some participants in this group might find the research methods terminology difficult to understand.

It was decided that the same number of participants as that of the healthcare providers' would be recruited in this study. Thirty participants would form a heterogeneous group for this study and the amount of data they would generate would be manageable. The task of finding 30 participants proved to be an arduous task. It took almost four months to approach and obtain consent from 30 cancer patients and carers, mainly due to the large number of cancer patients who are not aware of their diagnosis in Greece. The expert panel profile is described in table 3.4:

Table 3.4 The expert panel's profile for the study with the healthcare users

Participants	No
Cancer patients treated in oncology hospital	7
Cancer patients treated in general hospital	8
Carers of cancer patients in oncology hospital	7
Carers of cancer patients in general hospital	8
Total	**30**

The final panel consisted of adult patients with a variety of cancers (mainly breast cancer for the women and gastrointestinal cancer for the men). All patients in the panel had been informed of their diagnosis and had received some type of treatment at least once in the past. The carers who agreed to participate were caring for patients who were either in a fairly good condition or receiving palliative care both in the hospital and within the community. The cancer patients and carers were either from Athens or other parts of Greece and were recruited from four hospitals in total where they were being treated.

3.5.2 Delphi Questionnaires

Data process of collection regarding healthcare users' views consisted of two rounds. The purpose of the initial questionnaire was to identify the areas of cancer care and the cancer services that needed to be developed or improved in Greece. Responses to the first questionnaire were collated, analysed by a panel of experts and a second questionnaire was developed from these initial responses. The healthcare users were asked in the second questionnaire to rate the priority of each of the issues raised in round one. These ratings were collated and the consensual highest-rated responses were kept. This process is described in details in the following sections.

3.5.2.1 Q-Delphi 1st round

In the first round of both Q-Delphi studies, the same question was posed to healthcare providers and users. This was necessary as it could help future comparisons to be made between the two groups' views and priorities. The question was:

> *"In your opinion, which cancer services and which areas in cancer care, need to be developed or improved in Greece?"*

The question had previously been tested for the healthcare providers, thus it was not necessary to be pilot tested on patients and carers. A restricted response format was adopted in this round. The participants were asked to generate no more than five statements, so that the most important problems would be reported. The advantage of restricting the amount of statements the participants would offer was that it would

focus the respondents' attention and produce a list that would be short enough and could be effectively analysed.

3.5.2.2 Preparation for the 2nd round questionnaire

The statements received from round one were translated by the researcher from Greek to English. Two bilingual colleagues back-translated the statements. In 90% of the statements, the back-translation was identical. For the remaining 10% of the statements, the researcher met with the individuals who did the back-translation and agreed on the final translation of these items.

The suggestions proposed by the panel were transcribed using the Approach software programme by LOTUS Smart Suite. The items were given unique numbers to be identified with the respondents. The above mentioned software programme proved helpful in coding and sorting the data. Data collected from round one was of a qualitative nature and a content analysis approach was used to create themes under which the statements were then grouped. The content analysis was performed by a panel of researchers who were experts in content analysis. The process is described in chapter 5.2.1.1.

3.5.2.3 Q-Delphi 2nd round

The questionnaire for the second round included those statements provided by the panel from the first round under the themes created by the external panel who performed the content analysis (Appendix 11). The 30 panel members were asked to rate each statement on a seven point Likert type scale. The same type of scale was used for both healthcare providers and users.

The round two questionnaire was sent to all the members of the panel. The participants were given completion instructions. They were also asked not to rate the categories under which the statements were, but to rate each statement separately. An accompanying letter was included to acknowledge and thank the participants for responding in round one and asked them to return the completed questionnaire in the

free post envelope (Appendix 12). After four weeks, a reminder call was made to the participants who had not returned the questionnaires. On the eighth week, the second round was assumed to be complete as no further questionnaires had arrived. It was anticipated that some cancer patients or carers might be going through treatment or other difficult situations. For this reason, they were allowed more time to complete the questionnaire than the healthcare providers. One questionnaire by a patient arrived four months after the second round was assumed finished, hence it was not included in the analysis.

The data from round two were analysed using SPSS. Measures of central tendency (means) and level of dispersion (standard deviation) were computed for each of the items derived from the round one question. Correlation coefficients were computed for the ratings between the groups of cancer patients and carers. A positive correlation would indicate that high ratings in one group are associated with high ratings in the other group. A strong positive correlation coefficient would indicate a strong degree of agreement between the two groups.

3.5.2.3.1 Setting criteria for consensus

A large number of statements were highly rated by most of the participants suggesting that consensus could be achieved under certain criteria. The criteria set were that statements would be consensual if they had a mean score of six and above and that not been rated below five on the seven point Likert type scale. It was also decided to stop the Q-Delphi in round two as the objectives of the study had been achieved. It was anticipated that there was no reason to expose the participants to a stressful situation by asking them to rank in order the statements, as it was done with the healthcare providers. Over the course of the study, two of the cancer patients' health had deteriorated and one of the patients that was looked after by a carer had died. It was probable that a further round would have created unnecessary stress to the participants.

The following diagram (Figure 3.3) shows the process of the healthcare users' Q-Delphi study in a question mark format. It follows the classical Delphi process, as

presented in diagram 3.1, however there was an external panel who performed the analysis of the first round as opposed to other Delphi studies. In addition, there were only two rounds of questionnaires in opposition to the Q-Delphi study of healthcare providers that had three rounds.

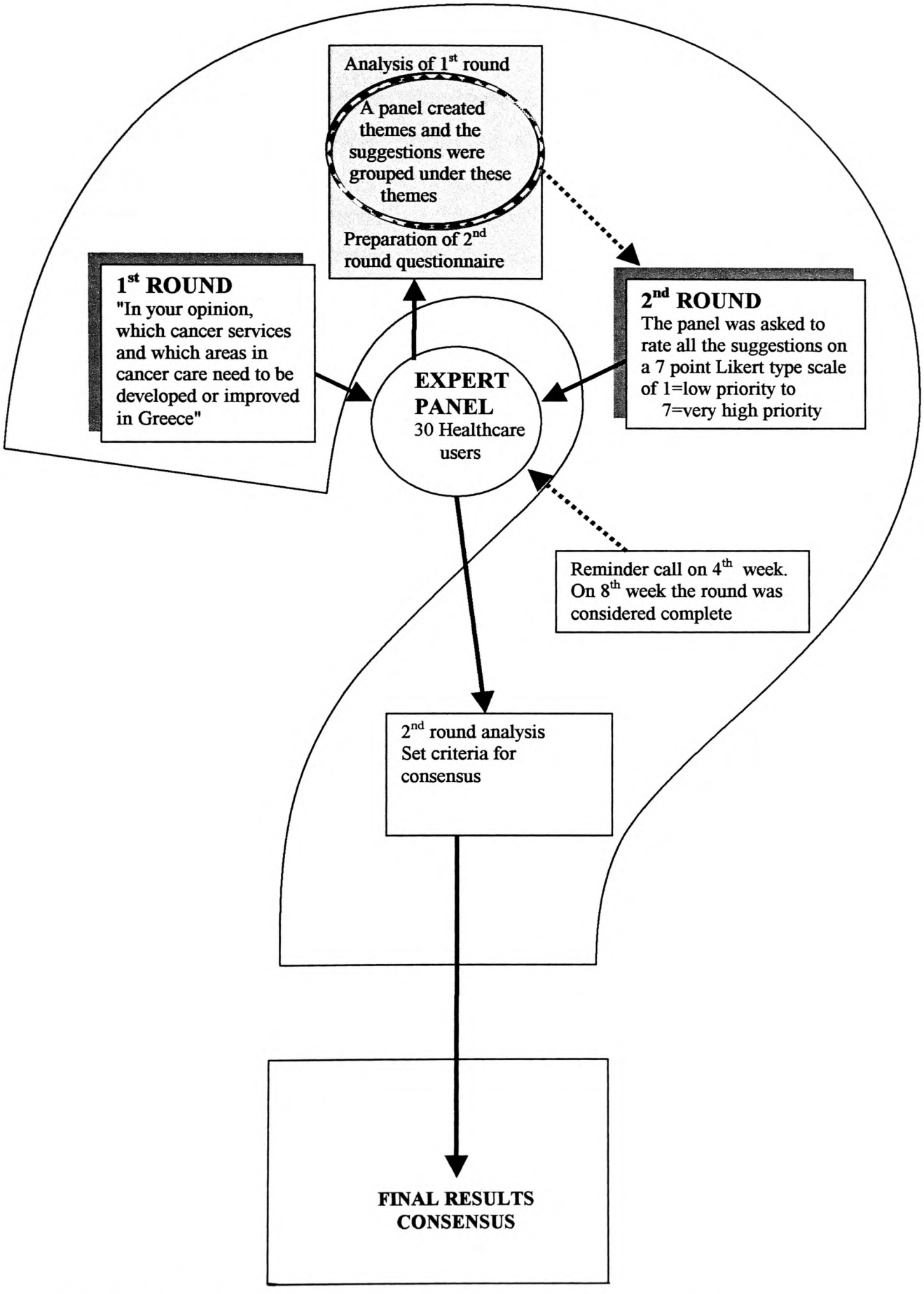


Figure 3.3 The flow chart of the healthcare users' Q-Delphi study

3.5.3 Sample Attrition

As stated in chapter 3.4.3, one of the problems in performing Delphi studies is that after the first round, panel members fail to respond (Bowles 1999). However, in this study a healthy response rate of over 70% was reached for the two rounds, thus maintaining the rigour of the technique (Sumsion 1998). The response rates for each round were 100% and 80% respectively. The researcher had personal contact with all the participants at the beginning and during the study as well as with the reminder calls which may have contributed to the satisfying response rates.

Taking into account the same reasons for sample attrition discussed in 4.4.7, within the study of healthcare users, these may be attributed to:

- Respondents may move during the study and cannot be traced;
  In the current study this was a problem as the participants could move during the study, or some of the cancer patients could have been hospitalised for a long period. Participants had only provided their home address and telephone number and it was difficult to trace them if they had moved.

- Elderly and infirm respondents may drop out due to ill-health or even death;
  This proved to be a problem in this study as the health of two cancer patients deteriorated and were not fit to fill the lengthy second round questionnaire. One cancer patient who was looked after by a carer died during the period of the study and the carer did not feel like completing the second round questionnaire.

- Respondents may lose interest in the study;
  This did not prove to be a problem in this study as there were no complains by any of the participants.

- Respondents may drop out because they are concerned about confidentiality and invaded privacy;

This issue did not pose a problem in this study as all the participants had received detailed information about Delphi technique with the first questionnaire and they were assured about confidentiality and anonymity.

3.6 HEALTHCARE PROVIDERS' AND HEALTHCARE USERS' VIEWS

After conducting two separate Delphi studies on which cancer services and areas of cancer care need to be developed or improved, one with healthcare providers and one with healthcare users, it was considered important to explore whether there were any shared views. Although the question was the same for both groups in round one, the statements generated regarding cancer care and cancer services were different. Therefore, it was not possible to compare healthcare providers' and healthcare users' views, depending on their ratings on the seven Likert type scale for the individual statements in round two. However, it was possible to compare the healthcare providers' and the users' views on the categories that were created by the external panel who undertook the content analysis after the first round of both Q-Delphi studies.

The average of the means of the statements under each category was computed in order to establish a mean score for each category. The aim was to prioritise the categories for each group according to their mean score. The variance on the ratings was also computed and precision means were calculated for each of the statements which resulted in a precision mean for each category. For the categories that both groups shared, the independent *t*-test was used. An independent t-test is a parametric statistical test used to examine the difference between the average measure of central tendancy of two different groups of subjects (Hicks 1999) and identifies whether there is a significant difference between the responses of two groups. In addition, Kendall's tau-b, a non parametric measure of association for ranked variables, was used on the categories that healthcare providers and users shared after they were ranked based on their precise mean scores. A positive coefficient would indicate an agreement between health care providers and users on their prioritisation.

3.7 CONSIDERATION OF OTHER METHODS

Before deciding to use the Delphi technique to gather data for the aim of this study, other methods were also considered. These are presented in the following section and described briefly. In addition, justification is given why they were not suitable for this study.

3.7.1 Questionnaires

Collecting data in surveys is usually through the use of a structured, semi-structured or focused questionnaire (Brink and Wood 1998). The purpose of the questionnaire is to collect specific information that will provide answers to the research question of a study (Cormack 2000). Questionnaires can be given to a large number of people, even by post, and subjects are more likely to express controversial opinions due to anonymity. They can collect unambiguous answers and are easy to analyse, making them relatively economical while large samples of people can be included (Bowling 1997).

However, constructing a questionnaire is a challenging process. Cormack (2000) suggests that the creation of a questionnaire should involve a critical analysis of the literature, group discussion with people similar to the sample, and testing ideas with experts taking into account the special needs of particular groups. In this study, the area of interest was not very well researched in Greece and the literature was limited. It could be argued that a questionnaire could be adopted from another country, however it would have to be translated and tested for its applicability to Greek culture.

Another reason for not using a questionnaire to collect data was that the pre-coded responses might not have been comprehensive or the answers might not have been easily accommodated, thus forcing the respondents to select inappropriate responses that might not represent their views. In this study, a questionnaire could have captured the respondents' views regarding the research question and also limited the respondents expressing their own views. While Delphi technique utilises questionnaires, there is a difference in that the participants themselves create the

questionnaires and through the rounds feedback is provided so that participants may change their views.

3.7.2 Interviews

Interviews may be conducted in a wide variety of research designs and the data usually generated are of peoples' experiences and accounts of events, their perceptions and opinions about phenomena, biographical and demographic details (Cormack 2000). In the qualitative tradition, the interviewer allows the interviewees to describe in their own words what is relevant and pertinent to them about the topic in focus (Cormack 2000). Furthermore, interviews tend to achieve high response rates reducing possible bias, the researcher knows that the participant is the intended respondent and they provide supplementary data that may be useful in interpreting responses (Polit and Beck 2004).

Although interviews allow for richer and more complex data to be collected (Grey 1998), they do have some disadvantages. Allowing interviewees to tell their stories without restriction, the researcher may end up with no information about the agreed topic of the interview. The appearance of the interviewer may also cause bias and may influence the respondent to answer in a certain way. It has also been noted that some subjects purposefully alter their behaviour because they are aware that they are taking part in a research study, a situation known as Hawthorne effect (Norwood 2000).

Interviews might have provided meaningful data for this study, but the question of generalisability would limit their potential use. Ong (1993) suggests that generalisation in qualitative research has been a contentious area as it builds on different assumptions in contrast to quantitative research, where probability is a key concept. In addition, interviews require considerable planning and interviewer training which can make them a rather costly procedure (Polit and Beck 2004).

3.7.3 Focus Groups

Focus groups are unstructured interviews with small groups of people who interact with each other and the group leader (Webb and Kevern 2001). As Kitzinger (1995) reports, the group processes may help people to explore their views in ways that would be difficult in face-to-face interviews.

Focus groups may stimulate discussion and provide rich data but there is no confidentiality in the group settings, and the presence of others can be inhibiting to some respondents. Some members of a focus group may conform to the majority opinion because of the group dynamic (Crawford and Acorn 1997). Furthermore, Smith *et al.* (1995) suggests that ethical issues should be considered when there is the potential for disclosure by the participants, particularly if the research topic is sensitive. This approach was considered inappropriate for the current study. The participants would be health providers, occupying different positions in the healthcare system or users with different backgrounds. Therefore it would be easy for some participants to conform to the most domineering members. In addition, the logistics of inviting health providers and users and obtaining their agreement to take part in the focus group would not be easy.

3.7.4 Nominal Group Technique

The Nominal Group Technique (NGT) is a special purpose group process appropriate for identifying elements of a problem situation, its solution programme and establishing priorities (Scott and Deadrick 1982). Although this method seems to avoid the known problems of group interviews, the participants still have to verbally announce their own ideas. That would restrict the expression of some ideas by non-articulated participants, especially when they are in a different position in the hierarchy. It would also be difficult to bring the participants for this study together as they would either be health professionals from a wide geographical area or cancer patients with a fragile health status and carers who usually spend most of their time with a terminally ill cancer patient. In addition, Rowe and Wright (1999) have reported that where Delphi technique and NGT have been compared they do not differ in accuracy and quality and in some cases Delphi technique has been superior.

3.8 SUMMARY OF METHODS AND RESEARCH DESIGN

In this chapter, Delphi technique was described as the preferred method for the purposes of the study. Delphi technique combines features of both qualitative and quantitative methods that make it more advantageous than other research methods. The recruitment process for the panel members of the two Delphi studies has been described and justified for their use in this study. A new Delphi technique was introduced as a modification of the existing technique, named Q-Delphi, by adding more objectivity on the research process. This was achieved by conducting a content analysis by a panel of experts rather than the researcher alone on the first round. The issue of translating qualitative type of data for the purposes of analysis was also addressed. Another adjustment of the classical form of Delphi technique was also introduced in this study by asking the participants to rank in order the consensual statements in the final round. The health care providers' Q-Delphi consisted of three rounds and the healthcare users' of two rounds.

In the next chapter, the World Health Organisation programme for controlling cancer will be presented as the theoretical framework to the current study.

CHAPTER FOUR

4. THE THEORETICAL FRAMEWORK OF THE STUDY

The objective of a theoretical framework is to provide a platform from which the findings from different data sources are justified and communicated within a wider context. In addition, a framework helps to summarise existing knowledge into coherent systems and stimulate new research by providing direction and impetus (Polit and Hungler 1999). In introducing the theoretical framework in this chapter, it must be noted that the main aim of this study was to establish strategies to improve cancer services and cancer care in Greece through exploring healthcare providers' and healthcare users' views. Indeed, their views could form the basis of recommendations in improving cancer services and cancer care which is a relatively new concept in Greece.

A yardstick was needed against which the views of both healthcare providers and users could be compared. It was anticipated that the priorities set by healthcare providers and users would reflect their views for better quality cancer services. The models that have been widely acknowledged for assessing quality of services are those of Donabedian (1982) and Maxwell (1984). Donabedian's (1980) classical framework "structure, process and outcome" is a well documented and widely used framework to assess the quality of services. Healthcare providers' and users' views on the healthcare system are by default an outcome of the services offered and it is clear that there are some aspects regarding the process of care that can only be assessed from the providers' and users' perspective. Healthcare providers and users may also have views upon the structure of care, such as the human, physical and financial characteristics of the service, as well as the experience of the process of care, such as the provision and reception of care (Hirst and Hewison 2001).

On the same concept, Maxwell (1984) documented his concern about the lack of quality in health care and proposed six dimensions of quality that needed to be assessed in healthcare (Table 4.1). The model that was devised by Maxwell is known

as 'Model of Quality'. This model has become a standard measure for quality and has been adapted for many uses in health care (Basset and McSherry 1996).

Table 4.1 The six dimensions of quality

Maxwell's model of Quality
Access to services
Relevance to need
Effectiveness
Equity
Social acceptability
Efficiency and economy

Source: Maxwell (1984) Quality assessment in health.

Furthermore, Maxwell (1992) developed Donabedian's (1980) original work by adding the six dimensions of the "model of quality" to the framework "structure, process and outcome" creating a grid (Table 4.2). The purpose of this grid was to expand, clarify and illuminate dimensions of quality in a systematic and structured way (Hirst and Hewison 2001). This was considered to be particularly beneficial for the quality assessments undertaken by the providers and users of healthcare (Maxwell 1992).

Table 4.2 Donabedian-Maxwell grid

	Structure	*Process*	*Outcome*
Effectiveness			
Acceptability			
Efficiency			
Access			
Equity			
Relevance			

Source: Maxwell (1992) Dimensions of quality revisited: From thought to action.

Both models have been applied in several areas of healthcare services in a systematic and logical way (Basset and McSherry 1996, Armes and Higginson 1999, Hirst and Hewison 2001). In the current study, the use of any of these models would help to clarify why the priorities raised by healthcare providers and users were seen as important and how they relate to the perceived quality of cancer services. However, quality is a term difficult to define and measure it in healthcare (Armes and Higginson 1999). This difficulty is also reflected on the effort by Maxwell (1992) to incorporate Donabedian's (1980) framework and the "model of quality" into a grid, so that quality in health care could be better assessed.

It was anticipated that these models would not provide an appropriate framework for the current study, as they would only clarify the views provided by healthcare providers and users. Furthermore, the aim was not to assess the quality of cancer care services, although the participants' suggestions would probably reflect this issue. Both models were also developed in countries different from Greece and have been focused more on the users' perspectives (Hirst and Hewison 2001). A model was needed that would justify and validate the priorities provided by healthcare users and providers from this study and be pertinent to Greece.

A further search for an up to date and practical theoretical model revealed a World Health Organisation's (2002) report that included guidelines and priorities for countries with different levels of resources available to establish cancer control programmes. Cancer control is defined as all actions that may reduce the burden of cancer in the community (Burton 2002). This report seemed to fulfill the criteria of providing a model that would help to compare and furthermore validate the results obtained from the current study. It was also country specific as it provided guidelines for countries with different levels of resources for healthcare. The relevant guidelines stated by WHO will be further explored in this chapter and will be used later as a yardstick against which the cancer services provision in Greece will be compared and future decisions to improve the services will be provided. Therefore, the final recommendations to improve or develop cancer services in Greece that will be provided from the current study will be based on the priorities set by the participants that would also be analogous to the suggestions by WHO for countries like Greece.

4.1 THE WORLD HEALTH ORGANISATION

The World Health Organisation, established during 1948, is the United Nations' specialised agency for health issues. All countries that are members of the United Nations may become members of WHO by accepting its constitution. Other countries may be admitted as members if their application is approved by a simple majority vote of the World Health Assembly. WHO is governed by 191 Member States through the World Health Assembly. Member States include developed as well as developing countries such as the United States of America, Greece, the United Kingdom and Uganda, who pay membership fees based on their population and income (Godlee 1994). The objective of this organisation is the attainment by all people of the highest possible level of health which is defined as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO 1990). The work of WHO can be epitomised in the broad areas that are presented in table 4.3.

Table 4.3 WHO philosophy

WHO provides: ▪ Information about disease outbreaks and trends; ▪ New developments in diagnosis, prevention, and treatment; ▪ Standards, technical manuals, and guidelines; ▪ Support for the development of health services and policy. WHO promotes: ▪ Efforts to control communicable and non-communicable diseases.

In the 1970s, WHO's famous document 'Health for All by the Year 2000' achieved the successful world-wide eradication of smallpox. Despite the enormous success of public health programmes recommended by WHO, the organisation has been recently accused of being bureaucratic, inefficient, unresponsive and unaccountable (Horton 2002). WHO, consisting of representatives from countries with different political backgrounds, is faced with political problems. Certain initiatives focusing on resource-poor countries, such as the 'essential drugs list', have faced political pressures from high industrialised countries (Horton 2002). WHO has also been

criticised as being incapable of responding to the fast changing challenges of international health (McCarthy 2002). The leaders of the World Health Organisation have often been attacked for the ineffectiveness of the organisation, although Godlee (1994) suggests that it is usually the structure and the management of the organisation which is to blame.

Despite the criticisms against WHO, the theoretical framework was still considered appropriate for use based on the idea that WHO occupies a unique position in the area of healthcare and represents a platform that can be used to bring about international collaboration in health research (Janca 2002). With regards the criticism that WHO has received, it has to be considered that WHO is not actively involved in implementing its propositions but acting through its member states and recommending directions for health policy. The access to data and information at international and national levels places WHO in a strong position for the credibility of the proposed rules and guidelines. Trostle *et al.* (1999) reporting on policy making in the healthcare area also suggest that WHO guidelines often are used by decision makers to develop public policies in various areas of healthcare. It was anticipated that the guidelines by WHO compared to the priorities agreed by healthcare providers and users for cancer care services in the current study would provide a set of powerful recommendations for Greek policy makers to consider.

4.2 THE MODEL PROPOSED BY WHO

For over a decade WHO has given priority to the prevention and treatment of non communicable diseases, such as cancer. Since 1948, WHO has regularly published reports on controlling cancer with the most recent published in 2002 (WHO 2002). This publication 'National Cancer Control Programmes: Policies and Managerial Guidelines', will form the theoretical framework of this thesis. According to this report, action should be taken in four areas: prevention, early detection, treatment and palliation. The actions should be planned and directed by a national cancer control programme. With careful planning and appropriate priorities within these four areas, the establishment of national cancer control programmes can offer the most rationale means of reducing the burden of cancer in the community.

It would be ideal if all countries could provide high quality cancer services for all people. However, due to economic restrictions, each country has to plan cancer services according to its available resources. As Lee and Mills (1982) have suggested, nations are faced with problems of slow or negative economic growth which have resulted in governments increasingly setting limits on distributing health resources. Health planning is needed in order to prevent waste and to make full use of resources. The aim of planning in health is to secure the provision of necessary services and a balanced relationship of health services with other social services at the lowest possible cost affordable by the country concerned (Abel-Smith 1994).

As all countries do not have the same resources to launch a cancer control programme, WHO (2002) has proposed three scenarios in guiding countries towards the implementation of cancer care services in accordance with their level of resources. According to their resources, countries fall into the low, medium or high resource level scenarios. These scenarios aim to identify specific actions to be taken that would be relevant to countries or even different population groups within a country. Each country, according to which level it falls within, is guided by WHO to establish national cancer control programmes in order to achieve acceptable standards in the areas of prevention, early detection, treatment and palliative care. For each level, the suggestions set by WHO form an 'ideal type' (Weber 1905).

The use of the 'ideal type' as a yardstick in this research has been derived from Weber (1905). Morrison (2000) describes the 'ideal type' as a way of selecting general concepts common to a range of phenomena. It is seen to represent a state which approximates the reality of a given society under certain conditions of its organisation. An ideal type involves the selection of empirical data and their conceptualisation. The selected features are then exaggerated to their logical extremes. The selection and exaggeration of these features are made in such a way that the complete construct has an inter-connected logical consistency (Salter 1998). An 'ideal type' therefore represents the essential features for any given situation or phenomenon, either positive or negative.

In the context of this research, the 'ideal type' consisted of a set of recommendations by WHO within the areas of cancer prevention, early detection, treatment and palliative care, based on three different scenarios which would in turn form the yardstick by which to compare the views of the healthcare providers and users obtained from the 'Delphi' studies.

It is interesting to note that the use of the 'ideal type' in this research goes beyond its known and classical use. As already stated, there are three different 'ideal type' scenarios. However, the model proposed by WHO is flexible in a way that if a region within a country of medium level resources has met the standards for this level, this region can opt for the higher level of recommended standards. Even for those countries that have reached the higher level of standards, WHO (2002) proposes to opt for even better provision of services in the areas of prevention, early detection, treatment and palliative care. These areas are not static, yet as new developments arise, it is possible and necessary for the standards to be revised. After considering the WHO scenarios for all the three level of resources, Greece was considered to be more appropriately allocated within the medium level scenario, the recommendations for which would form the yardstick by which to compare the research findings of the healthcare providers' and users' views (see section 4.2.2). Figure 4.1 shows the three different levels and the aims for each level.

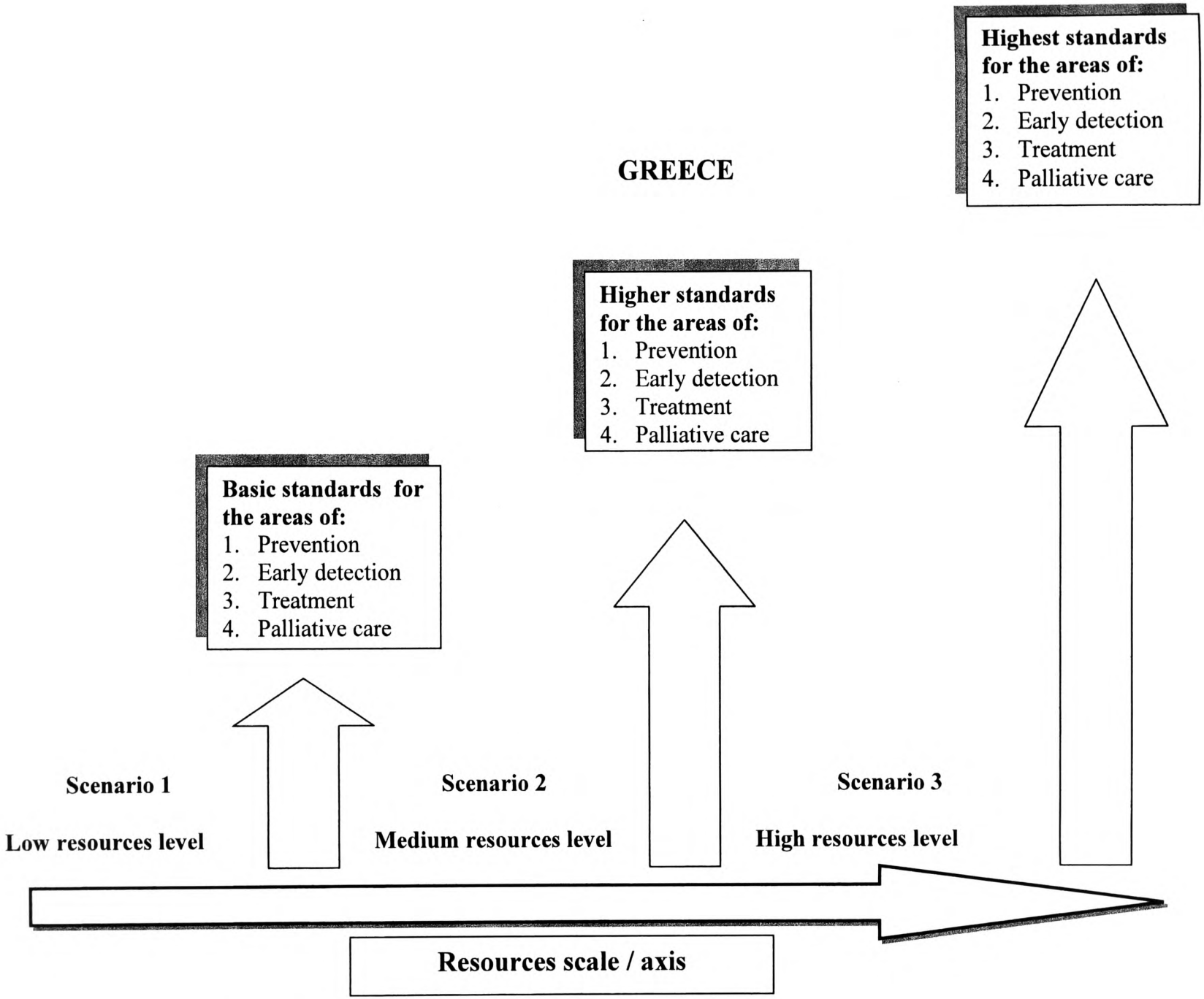


Figure 4.1 The three scenarios suggested by WHO

4.2.1 Criteria for Allocating a Country in One of the Scenarios

The WHO (2002) report provides information for allocating countries in one of the three scenarios. The scenario for low level of resources countries refers to countries where resources for chronic disease are very limited. These countries are considered developing, 'low income' countries, and suffer from social and political instability. A considerable proportion of the population is rural and mortality rates are high. Healthcare services are often delivered by informal means and infrastructure and human resources for cancer control are very limited (WHO 2002).

Countries in the medium level scenario are often considered 'middle-income' with a national income per person between US$ 756 and US$ 9265 (www.worldbank.org). The majority of the population is urban and life expectancy is over 60 years. Cancer is usually one of the leading causes of disease and mortality. There is also high exposure to risk factors, especially tobacco, diet, infectious agents, and carcinogens in the workplace. Infrastructure and human resources for developing cancer control are available but there are limitations in quantity, quality and accessibility of services. Weaknesses can be identified in the organisation, priority setting, resource allocation, and information systems for adequate monitoring and evaluation. Primary prevention and early detection are usually neglected in favour of treatment-oriented approaches, without much concern regarding their cost-effectiveness (WHO 2002).

The scenario for high level of resources countries is appropriate for industrialised countries with a relatively high level of resources for healthcare. In these countries life expectancy is over 70 years and cancer is a major cause of death for both men and women. Many elements of a cancer control programme are in place but they may not be integrated into a comprehensive national system. Furthermore, the provision of cancer services to the population may be uneven, with particular groups experiencing difficulties in accessing the services (WHO 2002).

4.2.2 Allocation of Greece in one of the proposed scenarios

Greece, according to the national income per person, provided by OECD (2002), is considered a 'high income' country. However, with US$ 10,700 income per person (GDP per capita), Greece is just over the boundaries of 'medium income' countries with the rest of the developed countries in Europe having over US$ 20,000 income per person (Table 4.4). Greece also spends one of the lowest percentages of Gross Domestic Product (GDP) on health among other countries in the European Union (OECD 2003) (Table 4.5).

Table 4.4 GDP per capita, 2001 (in US dollars) for the European Union countries

Country	GDP per capita
Luxemburg	43,400
Denmark	30,200
Ireland	26,600
Netherlands	23,900
United Kingdom	23,700
Sweden	23,600
Finland	23,500
Austria	23,300
Germany	22,500
Belgium	22,100
France	21,500
Italy	18,800
Spain	14,500
Portugal	10,900
Greece	**10,700**

Source: National Accounts of OECD countries, Main aggregates, Volume 1
Updated November 2002

Table 4.5 % of GDP spent on health (year 2001) for the European Union Countries

Country	% of GDP
Germany	8
France	7.2
Denmark	7.1
Portugal	6.3
Italy	6.3
Belgium	6.2 *
United kingdom	6.2
Netherlands	5.7
Sweden	5.9 *
Austria	5.6 *
Spain	5.4
Finland	5.3
Luxemburg	4.9 *
Greece	**4.7**

* Information provided is for year 2000
Source: OECD Health Data 2003

In Greece, over 60% of the population is urban. Life expectancy is over 70 years and cancer is one of the leading causes of death (WHO 2000). The problem of smoking is evident with 37% of the population who smoke (OECD 2002). The Mediterranean diet so far has provided a protective effect against cancer (Trichopoulou *et al.* 2000). Liver cancer incidence and mortality is higher compared to other European countries. A study of 333 Greek patients with liver cancer revealed that for 73% of the cases, Hepatitis B virus (HBV) or Hepatitis C virus (HCV) or both were responsible for causing liver cancer (Kuper *et al.* 2000). This could indicate that the high incidence of liver cancer in Greece is due to high exposure to HBV and HCV. Perdikaris *et al.* (2000) acknowledge that Greece belongs to the countries with medium incidence of HBV, however there are communities within Greece where the incidence is higher than 10%, a similar percentage to those countries with high incidence of HBV. In terms of exposure to carcinogens in the workplace, not enough information could be found in the Greek literature to validate this claim.

With regards to human resources within the Greek health system, it should be noted that only half of the estimated posts for nurses are filled in Greece and only 40% are fully qualified (Plati *et al.* 1998). The ratio of nurses to population is one of the

lowest in Europe, the overall ratio being 950 inhabitants per qualified nurse. However, the number of doctors is high with the overall ratio of 210 inhabitants per doctor being one of the highest in the European Union. The regional distribution of doctors is uneven with 58% of the doctors employed in the greater Athens and Thessaloniki area (Sigalas and Petraki 1999). As much medical expertise is located in either Athens or Thessaloniki, it is difficult for some patients to access it.

Petridou *et al.* (1999) report that there are no official governmental documents on healthcare priorities in Greece. The Greek attitude is one of addressing problems once they arise with notable disregard of cost effectiveness considerations. Most of the resources are also allocated in Athens or Thessaloniki (Giokas 2001). In addition, registration, a method of assessing the burden of cancer, does not exist in Greece at national level.

Health promotion has not yet been fully developed in Greece and national institutions for health promotion or health education do not currently exist. By contrast, initiatives are taken by scientific , non-governmental, non-profit making organisations such as the Greek Anti-Cancer Society and the Anti-Smoking Society (Petridou *et al.* 1999). Table 4.6 shows the criteria recommended by WHO (2002) for the medium and high level of resources in comparison with Greece.

It should be noted that Greece is a high income country with very high life expectancy and cancer is a major cause of death. According to the report by WHO (2002) Greece could be placed in the high level of resources scenario. However, the limitations in infrastructure and human resources, the weaknesses experienced in the health system and the findings of this research show that Greece has not met the medium level standards in the areas of cancer prevention, early detection, treatment and palliative care and should be placed in the medium better than the high level scenario.

Table 4.6 Greece compared to medium and high level resources countries

WHO **Medium Level of Resources Countries**	GREECE	WHO **High Level of Resources Countries**
▪ 'Middle income' countries	Just over the boundaries of 'middle income' countries	▪ Industrialised countries, high level of resources for healthcare
• Urban population	60% of the population is urban (WHO 1996)	
• Life expectancy over 60 years	Women 80.6 Men 75.5 (OECD 2002)	• Life expectancy over 70 years
• Cancer is a leading cause of diseases/mortality	24,027 cancer deaths out of 103,304 in total (www.statistics.gr)	• Cancer is a major cause of death
• High exposure to risk factors:		
Tobacco	37 % of population daily smokers (OECD 2002)	
Diet	N/A	
Infectious agents	HBV	
Carcinogens in workplace	Not reported	
• Infrastructure and human resources Limitations in:		• Many elements of a cancer control programme are in place
Quantity	Only four cancer hospitals. Few nurses	Uneven coverage of the population (Difficulty in accessing from rural areas/immigrants)
Quality	Many specialised doctors. Few qualified nurses	
Accessibility	Mostly concentrated in Athens	
• Weaknesses in:		• Weaknesses
Organisation	No official government papers on priorities. Problems are addressed once they arise without cost effectiveness considerations. Most of the resources available in Athens and Thessaloniki. No national registry.	Cancer control programme not well integrated into the national system
Priority setting		
Resource allocation		
Information systems		
• Primary prevention and early detection neglected in favor of treatment oriented approaches	Health promotion is not fully developed No national screening programme	

4.2.3 Standards to be Met by Medium Level Countries

In general, the primary prevention activities needed in this type of setting are tobacco control, reduction of alcohol use, and promotion of a healthy diet and physical exercise. Special attention should be paid to carcinogens in the workplace, and to infectious agents. Promotion of the warning signs for the common cancers should be encouraged. If rates of cervical cancer are high, the highest priority for a screening programme is cervical cytology screening. Screening for other types of cancers should be discouraged. Cancer treatment should focus on cancers that are curable, and clinical trials should be encouraged to evaluate relatively low-cost approaches that eventually can be provided to all patients irrespective of their socio-economic condition. More comprehensive approaches, such as radiotherapy and chemotherapy, should be introduced in specialised centres. Major efforts should be made to achieve the highest coverage for pain relief and palliative care, using low cost drugs and other interventions (WHO 2002).

4.2.3.1 WHO recommendations and Greece

According to the WHO (2002) theoretical framework, countries may have already developed cancer control activities and may have implemented certain recommendations. With regards to Greece, programmes like 'Europe against Cancer' have been widely discussed but with no action taken for its implementation. However, with the pressure from the international community, successive Greek governments have taken steps to control the tobacco epidemic. The per capita tobacco consumption in Greece still remains higher than in other European countries (Petridou *et al.* 1999), although there is some legislation prohibiting smoking in hospitals, schools, banks and public service settings. Papageorgiou (2000) in a comparative analysis of public health policies between Greece, England and Wales, reports that the current policies and priorities regarding tobacco control in Greece are less effective than those existing in England and Wales, and have been mainly focused on the evaluation of the problem.

The impact of hepatitis B virus has been acknowledged by the Greek state and since 1997, vaccination against HBV has been advised for new borns and adolescents (Perdikaris *et al.* 2000). Efforts are made to employ more qualified nurses, although the procedure is time consuming and bureaucratic. Some initiatives have also been taken to develop regional cancer registries (Vlahonikolis *et al.* 2002). Cervical screening, which is suggested by WHO (2002) for medium level of resources countries, has only been piloted in mainly rural regions of Greece (Riza *et al.* 2000). Mystakidou (2001) reports the lack of a national palliative care policy. However, efforts have been made to implement some aspects of palliative care in the form of pain relief in out patient clinics in some district hospitals.

Although the allocation of Greece in a scenario depending on the resources available posed difficulties, the medium level scenario was considered to be more appropriate as Greece has not achieved the recommendations by WHO (2002) for this level. The recommendations from the medium level scenario would be the 'ideal type' for Greece, the yardstick on which the views of healthcare providers and users would be compared. Table 4.7 shows the 'ideal type' for Greece, indicating where resources should be allocated at the medium level scenario in the areas of prevention, early detection, treatment and palliative care as they are described by WHO. The standards for countries of low and high level of resources are presented in Appendix 14.

Table 4.7 WHO standards to be met by medium level of resources countries

Component	All countries	Scenario B: Medium level of resources
National Cancer Control Programme	▪ Develop a national cancer control programme to ensure effective, efficient and equitable use of existing resources ▪ Establish a core surveillance mechanism to monitor and evaluate outcomes as well as processes ▪ Develop education and continuous training for healthcare workers	▪ When initiating or formulating a cancer control programme, consider implementation of a comprehensive approach in a demonstration area using a stepwise methodology ▪ Use appropriate technologies that are effective and sustainable in this type of setting
Prevention	▪ Implement integrated health promotion and prevention strategies for non-communicable diseases that include legislative/regulatory and environmental measures as well as education for the general public, targeted communities and individuals ▪ Control tobacco use, and address alcohol use, unhealthy diet, physical activity and sexual and productive factors ▪ Promote policy to minimise occupational-related cancers and known environmental carcinogens ▪ Promote avoidance of unnecessary exposure to sunlight in high risk populations	▪ Develop integrated clinical preventive services for counselling on risk factors in primary healthcare settings, schools and workplaces ▪ Develop model community programmes for an integrated approach to prevention of non-communicable diseases
Early diagnosis	▪ Promote early diagnosis through awareness of early signs and symptoms of detectable and curable tumours that have high prevalence in the community, such as breast and cervical cancer ▪ Ensure proper diagnostic and treatment services are available for the detected cases ▪ Provide education and continuous training to target populations and healthcare providers	▪ Use low cost and effective community approaches to promote early diagnosis of all priority detectable tumours
Screening	▪ Implement screening for cancers of the breast and cervix where incidence justifies such action and the necessary resources are available	▪ Provide national coverage cytology screening for cervical cancer at 5 year intervals to women aged 30 to 60 years
Curative therapy	▪ Ensure accessibility of effective diagnostic and treatment services ▪ Promote national minimum essential standards for disease staging and treatment ▪ Establish management guidelines for treatment services, essential drugs list, and continuous training ▪ Avoid performing curative therapy when cancer is incurable and patients should be offered palliative care instead	▪ Organise diagnosis and treatment services, giving priority to early detectable tumours or to those with high potential of curabililty
Pain relief and palliative care	▪ Implement comprehensive palliative care that provides pain relief, other symptom control, and psycho-social and spiritual support ▪ Promote national minimum standards for management of pain and palliative care ▪ Ensure availability and accessibility of opioids, especially oral morphine ▪ Provide education and training for carers and public	▪ Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care and nation-wide there is rising coverage of patients through services provided by primary healthcare clinics and home-based care

Source: WHO (2002) National Cancer Control Programmes. Policies and managerial guidelines.

4.3 SUMMARY OF THEORETICAL FRAMEWORK

The report by WHO (2002), 'National Cancer Control Programmes: Policies and Managerial Guidelines', provided the theoretical framework for this study, based on the allocation of countries in different levels, according to the resources available, with specific actions to be taken in order to lessen the burden of cancer in the community. The specific actions for each of the low, medium and high level scenario were considered as 'ideal type', derived from Weber's 'ideal type' (1905). Greece's 'ideal type' was the medium level scenario, based not only on the resources available but on what has been implemented so far in the control of cancer nationally. This 'ideal type', medium scenario's recommendations will be used as a yardstick to compare the views by healthcare providers and users in this research.

In the next chapter, the findings of the two Delphi studies are presented and critically discussed.

CHAPTER FIVE

5. FINDINGS

5.1 THE HEALTHCARE PROVIDERS' Q-DELPHI STUDY

5.1.1 Round One Q-Delphi Results

All the recruited sample members responded in round one, thus giving a satisfactory response rate of 100%. Participants were appointed under three groups; nurses 43.3%, doctors 33.4% and others 23.3%. It was not surprising that women represented 73.3% of the panel due to the large number of women in the caring professions. The average age of the panel was 39.2 years (SD=8.05) and the respondents' average years of experience in cancer care were 11.5 (SD=7.1). The panel's composition is described in table 5.1:

Table 5.1 Composition of the healthcare providers' panel

Gender	Doctor		Nurse		Other		Total	
	n	(%)	n	(%)	n	(%)	n	(%)
Male	8	(26.7)		0		0	8	(26.7)
Female	2	(6.7)	13	(43.3)	7	(23.3)	22	(73.3)
Total	10	(33.4)	13	(43.3)	7	(23.3)	30	(100)

The participants were asked to provide no more than five statements for the main question of the first round. One hundred and thirty five statements were generated by the participants. One participant provided only one statement, while five participants provided more than five statements. The average number of statements provided by each member of the panel was 4.5. Nurses, the biggest group in the panel, provided 69 statements (53%), doctors provided 31 statements (24%) and the rest of the health professionals provided 30 (23%).

A number of the statements received were detailed and contained several variables. For example, one nurse wrote:

> *"Day units should be developed as well as special intensive care units, physiotherapy units and home care services in all the oncology hospitals".*

Another respondent suggested:

> *"Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics".*

It was assumed that the experts in round two might face difficulties in rating responses that contained more than one variable. However, preservation of the meaning was important. For that reason, and in line with a purist Delphi approach, the statements were retained without editing. This approach asks panel members to interpret the respondents' statements even if they are vague, muddled or complex, and to make their own judgements independent of the researcher's influence (Mead and Moseley 2001). However, five statements were identical and were subsequently removed.

5.1.1.1 Categorisation of the 1st round statements

Following the collection of the first round questionnaire, it is usual to categorise the statements produced by the panel (Powell 2003). Data from the first round was qualitative by nature so a content analysis approach was used to identify themes under which the statements could be allocated. The process of categorisation has not attracted much attention among researchers of the Delphi technique. The existing guidelines for Delphi technique are not clear regarding the procedure of categorisation. In some studies the categorisation has been performed by only one person or the authors have failed to describe the procedure (Beech 1997, Love 1997, Gibson 1998). As there are no strict guidelines regarding the categorisation, Mead and Moseley (2001) have suggested the involvement of more than one researcher in the categorisation process with an aim to reach a high level of consensus on the

grouping of the statements. A similar strategy was followed in this study, but in order to avoid any inconsistencies in the developed categories and to ensure that the categories reflect the statements that they represent, this activity was conducted by a panel.

The panel consisted of the researcher and six other individuals: one Professor in nursing; a senior lecturer in nursing; and four research assistants. Each participant read the 130 statements separately, created themes and allocated the statements under these themes. In the next stage, the researcher collected all the suggestions and created a database with the statements and the suggested themes. If more than two of the panel had suggested the same theme for a statement, the statement was subsequently allocated under this theme. This action seemed to provide a more objective and valid second round questionnaire for the participants. Finally, 29 themes emerged from the content analysis and the 130 statements were allocated under these themes. For three statements the panel did not agree on the theme under which they should be allocated and hence, they were recorded under the miscellaneous category. Table 5.2 shows the themes that emerged together with their corresponding number of statements.

Table 5.2 Themes and number of statements

Themes from Round 1	No. of statements
Home care services	18
Education / Training	12
Public health / Health promotion	11
Psychological support	10
Special cancer units	7
Pain management	6
Financial resources	6
Staff shortages	5
Hospices	5
Research	5
Day units	5
Communication	4
Information	4
Prevention / Screening	3
Hospital environment	3
Health centres	3
Support	3
Organisation	3
Technology	3
Hostels for patients/relatives	2
Cancer registration	2
The stigma of cancer	1
Waiting lists	1
Working conditions	1
Special services	1
Networking	1
Occupational therapy	1
Education	1
Miscellaneous	3
Total	**130**

Fifty one statements (40%) were under the themes of home care, education/training, public health/health promotion and psychological support. Nurses, the largest group in the panel, offered most of the statements for these categories. Home care as a theme incorporated the highest number of statements. Surprisingly, doctors did not provide any statement under the theme of education/training. Table 5.3 shows the number of statements that were generated by the three groups in the panel of healthcare providers for the categories of home care, education/training, public health/health promotion and psychological support.

Table 5.3 Number of statements generated by healthcare providers by category

Themes	No of statements			
	Nurses	**Doctors**	**Others**	**Total**
Home care	12	2	4	18
Education / Training	8	0	4	12
Public health / Health promotion	7	3	1	11
Psychological support	4	2	4	10
Total	31	7	13	**51**

5.1.2 Round Two Q-Delphi Results

Twenty three questionnaires (77% response rate) were returned by the participants after rating. All three groups of health professionals were represented in this round. At least one expert from each of the groups returned a questionnaire after rating the statements. Table 5.4 shows the composition of the panel in round two.

Table 5.4 Composition of the healthcare providers' panel in round two

	Doctor		**Nurse**		**Other**		**Total**	
	n	(%)	n	(%)	n	(%)	n	(%)
Male	5	(21.7)		0		0	5	(21.7)
Female	2	(8.7)	11	(47.9)	5	(21.7)	18	(78.3)
Total	7	(30.4)	11	(47.9)	5	(21.7)	23	(100)

Mean scores and standard deviations (SD) were computed for each statement. Surprisingly, from the 130 statements, only 27 had a mean score lower than six (high priority). Seventy nine percent of the statements had a mean score of six and above (high to very high priority). One of the difficulties of Delphi studies, in which the panel provides statements and rate them, is that most of the suggestions are by definition desirable and tend to receive high ratings. The same issue has also been reported in other studies (Mead and Moseley 2001, Broomfield and Humphris 2001).

The statement:

> *"Home care should be developed for oncology patients not only during treatment but for terminally ill patients"*

was rated as very high priority by all the participants.

The main issues prioritised by the health professionals were the development of home care, the problem of staff shortages and the management of pain. Each of these issues was represented twice in the highest 10 rated suggestions. Other issues rated highly by the participants were psychological support, the provision of day units and communication. The following table 5.5, presents the 10 statements that were rated highest by the participants in order of their mean score.

Table 5.5 The 10 highest rated statements by healthcare providers

Statements	Mean	SD
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.00	0.00
102. Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services.	6.95	0.22
23. Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life.	6.86	0.35
50. Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics.	6.86	0.47
41. Day units should be increased in Oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients stay more at their home environment.	6.86	0.47
14. Screening services in hospitals should be operating for more hours, so that waiting lists get shorter (waiting period for a mammography may take 4 months).	6.83	0.65
103. The number of nursing staff should be increased in Oncology hospitals.	6.82	0.39
64. Psychological support should be provided to cancer patients and their families through all the stages of the disease.	6.78	0.52
53. Pain management services should be developed by pain clinics, offering pain management not only during treatment but also when at home, through all the stages of the disease.	6.77	0.53
81. The system connecting the health centres with the hospitals should be improved.	6.77	0.61

Since there were three groups in the panel, the five highest rated items for each group are presented in the following three tables 5.6, 5.7 and 5.8. Table 5.6 shows the five items rated the highest by the nurses. Nurses' three highest rated statements were under the category of home care. Pain management was also rated highly, as well as nurses' need for psychological support when working in special oncology hospitals.

Table 5.6 The five highest rated statements by nurses

Statements	Mean	SD
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.00	0.00
26. Home nursing services should be developed.	7.00	0.00
33. Home care nursing should be provided by all the Oncology hospitals in Greece.	7.00	0.00
50. Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics.	7.00	0.00
71. Psychological support for nurses working in Oncology wards. Support groups must be created by nurses for nurses in conjunction with counsellors.	7.00	0.00

Three of the five highest rated statements among the group of doctors were under the category of home care. The problem of nurse shortages in the area of home care services was also among the five highest prioritised items by doctors (Table 5.7).

Table 5.7 The five highest rated statements by doctors

Statements	Mean	SD
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.00	0.00
26. Home nursing services should be developed.	7.00	0.00
102. Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services.	6.86	0.38
22. Home care should be developed for cancer patients. This service is limited in the capital of Greece and non-existent in rural areas.	6.86	0.38
20. Cancer patients wherever they are nursed, they should receive the best treatment possible.	6.86	0.38

The remaining healthcare professionals who mainly offered support to cancer patients also rated home care the highest. The problem of nurse shortages is also present among the five highest rated statements. Stressful working conditions were also found to be a highly prioritised issue (Table 5.8).

Table 5.8 The five highest rated statements by the remaining healthcare professionals

Statements	Mean	SD
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.00	0.00
102. Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services.	7.00	0.00
23. Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life.	7.00	0.00
41. Day units should be increased in Oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients stay in their home environment for longer.	7.00	0.00
123. Working conditions must be improved so that working in a hospital becomes less stressful.	7.00	0.00

Table 5.9 shows the ten highest rated suggestions by the healthcare providers together with their rating by the three different groups in the panel. The highest rated ten statements by the healthcare providers were differently rated by the three groups in this panel. Seven of the 10 highest rated items were also rated highly by the nurses, nine by the other healthcare professionals and only four by the doctors. The statements are presented in rank order according to their mean scores.

Table 5.9 The 10 highest rated statements and their rank by each group in the panel

STATEMENTS	Nurses		Doctors		Others		All health providers	
	Mean	Rank	Mean	Rank	Mean	Rank	Mean	Rank
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.00	1	7.00	1	7.00	1	7.00	1
102. Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services.	7.00	1	6.86	3	7.00	1	6.95	2
23. Services like home care should be developed for terminally ill cancer patients for better quality of life at the last stages of life.	6.82	25	6.86	3	7.00	1	6.86	3
50. Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics.	7.00	1	6.57	16	7.00	1	6.86	4
41. Day units should be increased in Oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients stay in their home environment for longer.	6.82	25	6.83	9	7.00	1	6.86	5
14. Screening services in hospitals should be operating more hours, so that waiting lists are shorter (waiting period for a mammography may take 4 months).	6.91	9	6.57	16	7.00	1	6.83	6
103. The number of nursing staff should be increased in Oncology hospitals.	6.91	9	6.57	16	7.00	1	6.82	7
64. Psychological support should be provided to cancer patients and their families through all the stages of the disease.	6.91	9	6.43	29	7.00	1	6.78	8
53. Pain management services should be developed by pain clinics, offering pain management not only during treatment but when at home through all the stages of the disease.	6.91	9	6.57	16	6.75	45	6.77	9
81. The system connecting the Health Centres with the hospitals should be improved.	6.82	31	6.57	16	7.00	1	6.77	10

Despite the fact that 79% of the statements were rated very highly, there were other statements that received lower ratings. For example, statements relating to information giving to cancer patients by other healthcare providers, occupational therapy, and statements which referred to the organisation of local cancer services were rated lower. Table 5.10 shows the five lowest rated statements by healthcare providers.

Table 5.10 The five lowest rated statements by healthcare providers

Statements	Mean	SD
75. Volunteer and non-volunteer groups should be formed for giving information to cancer patients by the phone.	4.50	2.20
76. Services should be developed where cancer patients may receive information regarding their disease.	4.82	2.20
126. Cancer patients should be kept occupied at the hospital (occupational therapy)	4.95	2.08
15. Oncology units should be developed in general hospitals	5.00	2.23
59. Well organised oncology care in health centres	5.26	1.86

The expert panel of healthcare providers proved to have a very high rating pattern. Of the 23 participants in round two, 17 (74%) had a rating median of seven (very high priority), meaning that at least half of their ratings on the seven point likert type scale were at the highest end point of the scale. Only 8% of the participants had a median rating of five or below. Table 5.11 shows the median scores for the panels' rating in round two.

Table 5.11 The median scores from healthcare providers' ratings

Healthcare providers					
Median	Nurses	Doctors	Others	Total n	Total %
7	10	3	4	17	74
6	1	3	0	4	18
5	0	1	0	1	4
4.5	0	0	1	1	4

It was interesting to observe the five highest rated items for the group of the panel that had a lower median rating. Home care services were mentioned twice and were rated very highly by this group. The remaining suggestions rated highly were under the categories of prevention, communication and pain management. Even for this group of lower raters the statements highly rated are among those that are generally high rated by all the participants. Table 5.12 shows the five highest rated statements for the 26% of the participants who had a median rating between six and 4.5.

Table 5.12 The five highest rated statements by the healthcare providers who had lower rating attitude

Statements	Mean	SD
24. Services like home care should be provided by doctors, nurses and social workers	7.0	0.00
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients	7.0	0.00
12. Well organised screening programmes should exist for all the population, like PAP test or mammography, and not occasionally as it is currently	6.8	0.41
81. The system connecting the health centres with the hospitals should be improved	6.8	0.41
98. Education regarding pain management must be improved, so that pain may be treated even in primary health centres (health centres, out-patient clinics, etc.)	6.8	0.41

The correlation coefficients of the mean scores for each of the statements for the three groups in this Q-Delphi study were computed in order to observe if there was a significant relationship between the three groups. A positive correlation would indicate that when one group rated the statements highly, the other group would also rate them highly. A significant positive correlation coefficient was found between doctors and nurses; doctors and others; and nurses and others. The relationship was weak for the doctors and the others ($r=0.28$, $p<0.01$), and the nurses and the others ($r=0.35$, $p<0.01$). Not surprisingly, a moderate relationship was displayed for the doctors and nurses ($r=0.56$, $p<0.01$), as doctors and nurses tend to work together and share the same experiences. Table 5.13 describes the Pearson correlation scores for the three groups in the panel of healthcare providers.

Table 5.13 Pearson correlation for the groups within the healthcare providers' panel

Group	Pearson Correlation
Doctors - Nurses	0.559**
Nurses - Others	0.350**
Doctors - Others	0.278**
**p<0.01	

5.1.2.1 Consensus

Different approaches have been used to establish consensus criteria for prioritized items. For example, when the median has been used to suggest priorities, the interquartile range is used as the basis to judge whether there is a consensus on the prioritised statements. Similarly, in the case where the mean has been used to suggest priorities, the standard deviation has been used to differentiate between two statements with the same mean score. The greater the interquartile range or the standard deviation, the less consensus exists among participants. It was appropriate to set the criteria for consensus at this stage. Both approaches were tried but subsequently rejected.

When the median and the interquartile range were computed, even with a median of seven and the lower interquartile range, there were two statements that were rated as very low priority on the seven point Likert type scale by 4% of the participants in the second round, indicating that there was not a total consensus. In the case of the means and the standard deviations, if consensus was set for statements with a mean score of six or above and a standard deviation of less than one, there were two cases that statements were rated below four on the seven point Likert type scale. For this reason, stricter criteria were set. Statements considered consensual had to have a mean score of six and above and not be rated less than four (neither low nor high priority) on the seven Likert type scale by any of the respondents. Only 39 statements met these criteria (See Appendix 14).

5.1.2.2 Preparation for round three questionnaire

The 39 statements that met the consensus criteria formed the questionnaire for round three. As there was consensus on the priority for these 39 statements, it was appropriate to ask the participants to rank in order the most desirable suggestions. However, the number of statements was still high and that would pose difficulties for the respondents. For this reason, these statements were grouped under themes and the participants were asked to rank the statements under each theme. Grouping the statements in categories and asking the participants to rank the statements within each category was considered more efficient as the participants would need less effort in comparing the statements. Even with a small number of statements to be compared and ranked, the rater has to make too many comparisons.

After carefully reading the statements and in congruence with the themes suggested by the panel who performed the categorisation in round one, the statements were grouped under nine categories each containing three to six statements. The categories and the number of statements under each category for round three are described in table 5.14:

Table 5.14 Categories and number of statements for round three

Category	No of statements
Manpower resources	6
Organisational issues	4
Public health/Health promotion/ Prevention	3
Development of services	5
Equity in access of healthcare	3
Education / Training	5
Psychological support	5
Communication/Working conditions/Patient education	5
Palliative care/Pain management	3
Total	**39**

5.1.3 Round Three Q-Delphi Results

Twenty six questionnaires were completed and returned by the panel participating in round three of the Delphi method (a response rate of 86.7%). All health professionals were represented again in this round, from various healthcare settings as shown in table 5.15.

Table 5.15 Composition of the healthcare providers' panel in round three

	Doctors		Nurses		Others		Total	
	n	(%)	n	(%)	n	(%)	n	(%)
Male	6	(23.1)	0		0		6	(23.1)
Female	2	(7.7)	11	(42.3)	7	(26.9)	20	(76.9)
Total	8	(30.8)	11	(42.3)	7	(26.9)	26	(100)

The results are presented below for each category in the order they were presented in the 3rd round questionnaire. The statements are presented in rank order within each category with the percentage of the participants who ranked them as first, second and so on. A variation in the number of statements in each category did not allow comparisons to be made on categories, as in the smaller groups there is a greater chance for an item to be assigned a higher rank. This strategy is supported by Pelletier *et al* (1997) who also suggested that rankings in smaller thematic groups have less importance than rankings in groups with a large number of items. Since there were three groups in the panel, it was anticipated that they would rank in order differently the statements. Kruskal-Walis test was performed to examine the significance of differences in the rankings between the three groups.

1. Manpower resources

Under the category 'manpower resources' (Table 5.16) six statements were grouped regarding the shortage of health professionals in healthcare settings.

> *"The shortage of specialised nursing staff requires the immediate initiation and application of a plan for the recruitment and retaining of nurses in the profession"*

This statement was ranked first by 42.3% of the participants who returned the third round questionnaire. The statement that was ranked second in this category was more specific:

"The number of nursing staff should be increased in oncology hospitals",

and this was among the first 10 choices of the participants' ratings in round two. The following statement:

"Health centres should employ nurses so that home care services may be provided to the community around the health centres",

that was ranked third, revealed a significant disagreement among the panel members' rankings ($p<0.05$).

Table 5.16 Manpower resources statements' ranking

Statements	% of participants
The shortage of specialised nursing staff requires the immediate initiation and application of a plan for the recruitment and retaining of nurses in the profession.	42.3
The number of nursing staff should be increased in oncology hospitals.	26.9
Health centres should employ nurses so that home care services may be provided to the community around the health centres.	11.5 *
Oncology wards should be staffed with social worker and psychologist.	7.7
Services like home care should be provided by doctors, nurses and social workers.	7.7
Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services.	3.8
* $p<0.05$ Kruskal-Wallis	

2. Organisational Issues

This category contained four statements regarding the 'organisation' of cancer services. Sixty one percent of the participants ranked this statement first:

> *"Oncology hospitals must become independent, functional, efficient, non-bureaucratic. The environment of oncology hospitals should not seem impersonal".*

This statement incorporated many important issues, leaving the rest of the statements with less than 39% of the participants ranking them first. Surprisingly, this statement on the 2nd round was not highly regarded. On the contrary, the statement ranked last in this category was among the first ten in round two (Table 5.17).

Table 5.17 Organisational issues statements' ranking

Statements	% of participants
Oncology hospitals must become independent, functional, efficient, non bureaucratic and human. The environment of oncology hospitals should not seem impersonal.	61.5
A registration programme of all the cancers on national level must be developed.	15.4
There should be wiser financial arrangements so money will not be wasted. Money should be spent wisely for equipment and machinery necessary for the treatment of cancer patients.	15.4
The system connecting the health centres with the hospitals should be improved.	7.7

3. Public health / Health promotion / Prevention

Three statements were under this category as shown in table 5.18. Health professionals stressed the need for

"media to inform people about cancer prevention".

Under this category no marked difference could be found in the ranking of the statements. The first statement was ranked first by 38% of the participants, while the remaining two were ranked second and third by 31% of the participants respectively. Again the first ranked statement was not among the first ten in round two, while the third ranked statement was among the first ten in round two. The ranking in the third round did not show marked differences among the three statements assuming that they were desired by all the participants.

Table 5.18 Public health / Health promotion / Prevention statements' ranking

Statements	% of participants
Media should inform people about cancer prevention	38.5
Cancer prevention programmes must be developed with the co-operation of all health professionals	30.8
Screening services in hospitals should be working more hours, so that waiting lists may get shorter (waiting period for mammography may take 4 months)	30.8

4. Services development

The category of 'services development' consisted of five statements, described in table 5.19. More than half of the participants (54%) ranked the following statement first:

"Day Units, special intensive care units, home care services should be developed by all Oncology Hospitals"

This statement was very general and incorporated suggestions in statements that were ranked lower by the participants in this category.

> *"Home care should be developed for oncology patients not only during treatment but for terminally ill patients"*

This statement was ranked fourth, while in the second round of the Q-Delphi, it was the statement that was rated as a very high priority by all the participants. The possible reason for this statement being ranked fourth in this category was that the first ranked statement incorporated the development of day units, special intensive care units, physiotherapy and home care services. Respondents ranked the statement that was categorised second significantly differently ($p<0.05$). None of the nurses highly ranked this particular statement.

Table 5.19 Services development statements' ranking

Statements	% of participants
Day units should be developed as well as special intensive care units, physiotherapy units and home care services by all oncology hospitals.	53.8
Pain management services should be developed by pain clinics, offering pain management not only during treatment but whilst staying at home, through all the stages of the disease.	19.2*
Day units should be increased in oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients may remain more in their home environment.	11.5
Home care should be developed for oncology patients not only during treatment but for terminally ill patients.	7.7
Home care services should be provided by all oncology centres.	7.7
* $p<0.05$ Kruskal-Wallis	

5. Equity in access of healthcare

The accessibility of cancer services is a major issue in most countries. Under the category of 'equity in access of healthcare', there were three statements (Table 5.20). The statement ranked first by over half of the healthcare providers was the statement:

> *"Cancer hospitals should be built in different areas of Greece so that cancer patients will not have to travel far for special treatment".*

Table 5.20 Equity in access of healthcare statements' ranking

Statements	% of participants
Cancer hospitals should be built in the greater area of Greece so that cancer patients will not have to travel far for special treatment.	53.8
Insurance companies should cover cancer patients during all the phases of the disease (diagnosis, treatment, rehabilitation).	26.9
Doctors in oncology hospitals and nurses should be specialised to offer personalised care to cancer patients, e.g. pain management, vomiting, quality of life.	19.2

6. Education/Training

The category 'education/training' consisted of five statements (Table 5.21).

> *"Education (basic, post- and continuing) must be improved for all health professionals (doctors, nurses, psychologists, social workers, etc.)"*

This statement was ranked first by 39% of the participants. This statement was general in scope, while the remaining statements were focused on education specifically in the oncology area. The statement ranked last in this category referred to the organisation of a cancer nursing specialty.

Table 5.21 Education / Training statements' ranking

Statements	% of participants
Education (basic, post basic and continuing) must be improved for all health professionals (doctors, nurses, psychologists, social workers).	38.5
There should be opportunities for basic and post basic education for all health professionals in oncology wards. Education programmes should be organised as well and nurses should have the opportunity to take part in order to improve the provision of nursing care.	19.2
Doctors and nurses should be educated so that they can recognise cancer symptoms at an early stage and diagnosis may be made as soon as possible.	19.2
Emphasis should be given to staff's education in special oncology hospitals.	15.4
Educational centres must be developed to provide an oncology nursing specialty.	7.7

7. Psychological support

Five statements addressed the category of 'psychological support' as shown in table 5.22.

> *"Psychological support groups must be created in Oncology Hospitals, consisting of psychiatrist, nurses, psychologist, social workers etc.".*

This was the highest ranked statement by 46.2% of the participants. The statement that suggested psychological support for nurses who work in oncology hospitals was ranked fourth.

Table 5.22 Psychological support statements' ranking

Statements	% of participants
Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist and social workers.	46.2
Psychological support groups must be created for the support of patients and families not only in the hospital but in the community as well.	19.2
Psychological support should be provided to cancer patients and their families through all the stages of the disease.	15.4
Psychological support for nurses working in oncology wards. Support groups must be created by nurses for nurses in conjunction with counsellors.	12
Psychological support should be given by professionals not only on diagnosis but during treatment too.	7.7

8. Communication / Working conditions / Patient Education

In the category 'communication / working conditions / patient education' three statements addressed the need for training in communication skills while the remaining statements addressed the issues of stress in the clinical settings and the need for young cancer patients to continue their education while at hospital (Table 5.23). Sixty five percent of the health professionals ranked the following statement first.

> *"All health professionals who come in contact with cancer patients should receive special training in communication skills (How to tell the diagnosis, bad news regarding the treatment etc.)".*

Table 5.23 Communication / Working conditions / Patient Education statements' ranking

Statements	% of participants
All health professionals who come in contact with cancer patients should receive special training in communication skills (how to tell the diagnosis, bad news regarding treatment, etc.).	65.4
Working conditions must be improved so that working in a hospital becomes less stressful.	15.4
All health professionals should attend seminars on communication skills.	11.5
Doctors and nurses must get communication improvement courses.	3.8
There should be the possibility for young cancer patients to continue their education at the hospital.	3.8

9. Palliative Care / Pain Management

The last category 'palliative care / pain management' consisted of three statements (Table 5.24). Forty six percent of the participants ranked the following statement first:

> *"Development of terminal care for the patients either at home or in special hospitals and institutions".*

Table 5.24 Palliative care/Pain management statements' ranking

Statements	% of participants
Development of terminal care for the patients either at home or in special hospitals and institutions.	46.2
Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics.	38.4
Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life.	15.4

The decision for ranking the statements in order of their importance in round three proved to be helpful. Participants were asked to prioritise the statements by ranking them under certain categories. These decisions were not made easily in round two as most of the statements were rated highly by almost all the participants. The participants' highest ranked priorities have been summarised and presented in the following table (Table 5.25)

Table 5.25 The highest ranked priorities by healthcare providers

1.Manpower resources	The shortage of specialised nursing staff requires the immediate initiation and application of a plan for the recruitment and retaining of nurses in the profession.
2. Organisational issues	Oncology hospitals must become independent, functional, efficient, non-bureaucratic. The environment of oncology hospitals should not seem impersonal.
3. Public health / Health promotion / Prevention	Media should inform people about cancer prevention
4. Services development	Day units should be developed as well as special intensive care units, physiotherapy units and home care services in all the oncology hospitals
5. Equity in access of healthcare	Cancer hospitals should be built in the greater area of Greece so that cancer patients will not have to travel far for special treatment
6. Education/Training	Education (basic, post basic and continuing) must be improved for all health professionals (doctors, nurses, psychologists, social workers).
7. Psychological Support	Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist and social workers.
8. Communication / Working conditions / Patient education	All health professionals who come in contact with cancer patients should receive special training in communication skills (How to tell the diagnosis, bad news regarding the treatment etc.).
9. Palliative care / Pain management	Development of terminal care for patients either at home or in special hospitals and institutions

To establish whether there was within group agreement, the responses from nurses, doctors and other healthcare providers were analysed separately using the Kendall coefficient of concordance (Kendall's W). This is a non-parametric test which can be used with correlational and ordinal data to assess the extent of agreement between three or more sets of data (Hicks 1999). As expected, a significant level of correlation was found between:

- The nurses' rankings (χ^2=141.351, d.f.=38, p<0.001) Kendall's W=0.338;
- The doctor's rankings (χ^2=107.609, d.f.=38, p<0.001) Kendall's W=0.354;
- The remaining of health professionals' rankings (χ^2=99.459, d.f.=38, p<0.001) Kendall's W=0.374.

5.2. THE HEALTHCARE USERS' Q-DELPHI STUDY

5.2.1 Round One Q-Delphi Results

All the recruited sample members responded in round one with a satisfactory response rate of 100%. Participants were allocated into four groups; 23.3% cancer patients treated in cancer hospitals, 26.7% cancer patients treated in general hospitals, 23.3% carers whose patients were treated in cancer hospitals and 26.7% carers whose patients were treated in general hospitals. Not surprisingly, 80% of the sample was female as the carer's role is undertaken by a female member of the family in the Greek culture. The composition of the healthcare users panel is presented in table 5.26.

Table 5.26 Composition of the panel for the healthcare users' study

Gender	Patient CH*		Carer CH*		Patient GH**		Carer GH**		Total	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Female	7	(23.3)	7	(23.3)	5	(16.7)	5	(16.7)	24	(80)
Male		0		0	3	(10)	3	(10)	6	(20)
Total	7	(23.3)	7	(23.3)	8	(26.7)	8	(26.7)	30	(100)

* Cancer hospital
** General hospital

The mean age for cancer patients was 54 years (SD=9.1) and the average period they had cancer was 5.9 years (SD=2.4). For the carers the mean age was 42.6 years (SD=7.4) and it was difficult for them to provide information on how many years they were caring for their cancer patients as there were periods that no form of caring was offered.

The participants were asked to provide a maximum of five suggestions for the main question of the first round. One hundred and twenty three statements were generated in response to this question. The maximum number of statements expected was 150. That shows that even if there was no restriction of five statements from each participant, there would not be more statements. The average number of statements generated by the participants was four. One participant provided only one statement,

while four participants provided more than five statements. The carers whose patient were treated in a general hospital provided 39 statements (32%), the patients treated in a general hospital provided 34 statements (28%), the patients treated in an oncology hospital provided 27 statements (22%) and the carers whose patient were treated in an oncology hospital provided 23 statements (18%).

Some of the statements received were detailed and contained many variables, as was the case in the study with the healthcare providers. It was assumed that the experts in round two might face difficulties in rating responses which contained more than one variable. However, as the preservation of the meaning was important and in line with a purist Delphi approach, the statements were retained without editing.

5.2.1.1 Categorisation of the 1st round statements

A panel of six healthcare researchers who were experts in content analysis including the researcher read the 123 statements carefully, created themes and allocated the statements under these themes, independently of each other. In the next stage, the researcher collected all the panel suggestions and created a database with all the statements and the suggested themes. If more than two of the panel had suggested the same theme for a statement, the statement was allocated under this theme. Finally, 27 themes emerged from the content analysis and the 123 statements were allocated under these themes. The following table (Table 5.27) shows the themes that emerged with their corresponding number of statements.

Table 5.27 Themes and number of statements

Themes obtained from Round 1	No of statements
Education / Training	11
Resources	11
Psychological support	11
Information	11
Organisation	8
Public health / Health promotion	8
Special cancer units	7
Staff attitude	6
Pain management	6
Technology	5
Staff shortages	5
Home care	5
Hospices	4
Communication	4
Extra costs	3
Treatment	2
Research	2
Finance	2
Extra beds	2
Day units	2
Hospital environment	2
New treatment	1
Staff skills	1
Stigma	1
Support	1
Networking	1
Satisfaction	1
Total	**123**

Forty four statements (36%) were listed under the categories of education / training, resources, psychological support and information. Each group generated almost the same number of statements for the categories of psychological support and information, as shown in table 5.28.

Table 5.28 Number of statements generated by healthcare users by category

Categories	Patient CH*	Patient GH**	Carer CH*	Carer GH**	Total
Education / Training	3	4	1	3	11
Resources	3	1	6	1	11
Psychological support	3	2	2	4	11
Information	2	4	3	2	11
Total	**11**	**11**	**12**	**10**	**44**

*CH: Cancer hospital
**GH: General hospital

5.2.2 Round Two Q-Delphi Results

Twenty four questionnaires were returned with a response rate of 80%. All the groups were represented in the second round with only the percentage of cancer patients treated in general hospitals falling from 26.7% in the original panel to 20.8% in the second round (Table 5.29).

Table 5.29 Composition of the healthcare users' panel in round two

Gender	Patient CH*		Carer CH*		Patient GH**		Carer GH**		Total	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Female	6	(25)	6	(25)	3	(12.5)	4	(16.7)	19	(79.0)
Male		0		0	2	(8.3)	3	(12.5)	5	(21.0)
Total	6	(25)	6	(25)	5	(20.8)	7	(29.2)	24	(100)

*Cancer hospital
**General hospital

The mean scores and standard deviations (SD) were computed for each statement. When the mean scores were examined, it was found that among the 123 statements, only half had a mean lower than 6 out of a maximum of 7. None of the statements was rated as a very high priority by all the participants. The main issues prioritised by the healthcare users were the education of health professionals and treatment. Each of these issues was mentioned twice in the first ten highly rated items. The organisation of cancer services, the need for more resources, and the attitude of healthcare professionals were also rated highly (Table 5.30). In general healthcare users are concerned about timely diagnosis and treatment by well educated healthcare professionals. They have allocated high rates to issues related to their survival.

Table 5.30 The 10 highest rated statements by healthcare users

Statements	Mean	SD
13. All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning.	6.75	0.53
45. New ways of treatment should be found, more effective.	6.63	0.49
53. Better allocation of the CAT scans and all the special equipment and not consolidation in Athens and Thessaloniki.	6.63	0.71
16. Doctors and nurses who work in special cancer centres should be properly educated.	6.58	0.58
87. First of all, there should be enough space, because it is not fair for 16 patients to be in the same room, and it is depressing for somebody at the beginning of the disease to watch somebody in the last stages.	6.58	0.72
119. There should be a possibility for patients with aggressive cancer to be treated out of waiting lists.	6.58	0.72
19. The Greek state should give more attention in the area of health, patients should not be nursed in the corridors.	6.54	0.88
20. Free drug provision by all insurance companies.	6.54	0.72
116. Hospitals should provide the appropriate equipment and the appropriate specialised staff.	6.54	0.59
100. Doctors should give more attention and provide more time for the examination of the patients.	6.54	1.02

In the panel of the healthcare users, there were four groups (cancer patients treated in oncology hospitals, carers caring for a patient treated in an oncology hospital, cancer patients treated in general hospitals and carers caring for a patient treated in a general hospital). The five highest rated statements for each of the groups are presented in the

following four tables 5.31, 5.32, 5.33 and 5.34. Cancer patients who were treated in a cancer hospital highly rated statements that were under the categories of treatment, research, finance and hospices (Table 5.30). In summarising the five highly rated items in this group, it seems that cancer patients were concerned about their treatment which they wanted fast, effective, with less side effects and free of charge. The issue of palliative services development was also raised.

Table 5.31 The five highest rated statements by cancer patients treated in cancer hospitals

Statements	Mean	SD
119. There should be a possibility for patients with aggressive cancer to be treated out of waiting lists.	6.83	0.41
80. Research should be done in order to find better ways to treat chemotherapy side effects.	6.83	0.41
45. New ways of treatment should be found, more effective.	6.67	0.52
20. Free drug provision by all insurance companies.	6.67	0.52
28. There should be special places for patients who are in the final stages of the disease, who need special care.	6.67	0.52

Two of the five highest rated items among the group of carers of patients treated in cancer hospital were under the category of health professionals' education. This group was also concerned about the treatment offered. The supplying of analgesia was also among the five highest prioritised issues in this group. Table 5.32 shows the five highest rated statements for this group.

Table 5.32 The five highest rated statements by carers in cancer hospitals

Statements	Mean	SD
13. All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning.	6.83	0.41
45. New ways of treatment should be found, more effective.	6.67	0.52
16. Doctors and nurses who work in special cancer centres should be properly educated.	6.67	0.52
55. The procedure of supplying narcotic analgesics to patients must be improved.	6.67	0.52
88. Improvement of the wards. Less beds in the rooms.	6.67	0.52

The group of cancer patients who are treated in general hospitals rated statements under the categories of resources, health professionals' education, organisation and health professionals' attitudes highly as shown in table 5.33. This group was mainly concerned about timely diagnosis and treatment in a good hospital environment.

Table 5.33 The five highest rated statements by cancer patients treated in general hospitals

Statements	Mean	SD
13. All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning.	7.00	0.00
88. Improvement of the wards. Less beds in the rooms.	7.00	0.00
87. First of all, there should be enough space, because it is not fair for 16 patients to be in the same room, and it is depressing for somebody at the beginning of the disease to watch somebody on the last stages.	7.00	0.00
100. Doctors should give more attention and provide more time for the examination of the patients.	7.00	0.00
53. Better allocation of the CAT scans and all the special equipment and not consolidation in Athens and Thessaloniki.	7.00	0.00

It was only carers of those patients treated in general hospitals who rated the issue of having to pay extra money for getting better attention by the doctors the highest. For this group the items that suggested organisation of services so that patients are treated in one place were highly rated as well. Home care was also highly rated by this group (Table 5.34).

Table 5.34 The five highest rated statements by carers in general hospitals

Statements	Mean	SD
121. There should not be a need to give money to doctors in the hospital for better attention.	7.00	0.00
53. Better allocation of the CAT scans and all the special equipment and not consolidation in Athens and Thessaloniki.	6.86	0.38
23. Expansion of home care so that patients may die in their known environment, with dignity and the love of their relatives.	6.86	0.38
48. Cancer patients' tests should be completed where they are nursed, so that they do not have to be transferred in other hospitals.	6.86	0.38
116. Hospitals should provide the appropriate equipment and the appropriate specialised staff.	6.86	0.38

Table 5.35 shows the ten highest rated statements by the healthcare users and their rating by the four different groups in the panel. The ten highest rated statements by the healthcare users were differently rated by the four groups in this panel. Eight of the ten highest rated statements by the entire panel were also in the ten highest rated items by the cancer patients treated in a general hospital, only three by the carers of those patients treated in a general hospital and five statements for both cancer patients in cancer hospitals and carers from cancer hospitals. The statements are presented in rank order according to their mean score after rating by all healthcare users.

Table 5.35 The 10 highest rated statements and their rank by each group

STATEMENTS	General hospital patients		General hospital carers		Cancer hospital patients		Cancer hospital carers		All healthcare users	
	Mean	Rank	Mean	Rank	Mean	Rank	Mean	Rank	Mean	Rank
13. All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning.	7.00	1	6.71	7	6.50	10	6.83	1	6.75	1
45. New ways of treatment should be found, more effective.	6.60	20	6.57	16	6.67	3	6.67	2	6.63	2
53. Better allocation of the cat scans and all the special machinery and not consolidation in Athens and Thessaloniki.	7.00	1	6.86	2	6.50	10	6.17	19	6.63	3
16. Doctors and nurses who work in special cancer centres should be properly educated.	6.80	7	6.57	16	6.33	24	6.67	2	6.58	4
87. First of all, there should be enough space, because it is not fair for 16 patients to be in the same room, and it is depressing for somebody at the beginning of the disease to watch somebody in the last stages.	7.00	1	6.43	32	6.50	10	6.50	6	6.58	5
119. There should be a possibility for patients with aggressive cancer to be treated out of waiting lists.	6.80	7	6.57	16	6.83	1	6.17	19	6.58	6
19. The Greek state should give more attention to the area of health, patients should not be nursed in the corridors.	6.80	7	6.71	13	6.33	24	6.33	11	6.54	7
20. Free drug provision by all insurance companies.	6.80	7	6.57	16	6.67	3	6.17	19	6.54	8
116. Hospitals should provide the appropriate equipment and the appropriate specialised staff.	6.60	20	6.86	2	6.17	39	6.50	6	6.54	9
100. Doctors should give more attention and provide more time for the examination of the patients.	7.00	1	6.57	16	6.33	24	6.33	11	6.54	10

It has been mentioned (chapter 5.2.2.) that half of the 123 statements received a mean score of six and above by the participants, however there were statements that received very low ratings. Healthcare users were not uniformly undiscriminating. For some items, respondents gave a rating of two or one on the seven point Likert type scale and some mean scores were low. Table 5.36 shows the five lowest rated statements among the healthcare users. The statement that has been rated lower by the participants in this round was the one that expressed a positive view about the healthcare professionals and the hospitals where care was offered.

Table 5.36 The five lowest rated statements by healthcare users

Statements	Mean	SD
92. My views regarding the staff and the place of treatment are positive.	3.96	1.63
9. The nursing staff in general hospitals are uninterested and they are not educated to treat cancer patients.	4.63	1.44
33. National information net.	4.88	1.33
44. There should be a kind of place where all the oncologists could meet and exchange views and information.	4.88	1.73
105. A lot of doctors do not inspire the feeling of trust to the patients and their relatives, so patients prefer to go abroad for better diagnosis and treatment.	5.00	1.35

As there were four groups in this Delphi study, the correlation of the mean scores of the statements would show how these groups were associated with regards to their ratings. A strong correlation coefficient would mean that if one group had rated a statement highly, the other group would have also done the same. A significant positive correlation was found between the scores obtained from all the groups within the healthcare users. The correlation coefficient was weaker for the groups of carers who cared for a patient either treated in a general or cancer hospital, and the carers who cared for patients treated in general hospital and the patients treated in cancer hospitals. The highest correlation coefficient was observed between the patients in general and cancer hospitals, probably due to the similarities of experiences among those two groups. The following table (Table 5.37) shows the Pearson's Moment-Product Correlation between the statements' mean scores for the four groups.

Table 5.37 Pearson correlation for the groups within the healthcare users' panel

Groups of participants	Patients General Hospital	Patients Cancer Hospital	Carers General Hospital	Carers Cancer Hospital
Patients General Hospital	x	0.605**	0.581**	0.580**
Patients Cancer Hospital	x	x	0.480**	0.580**
Carers General Hospital	x	x	x	0.441**
Carers Cancer Hospital	x	x	x	x
**p<0.01				

5.2.2.1 Consensus

The experience gained from the adoption of the Q-Delphi study with the healthcare providers suggested the application of the same strategy for consensus for the healthcare users' study. However, for this study, the criteria were narrower. In the Q-Delphi study with the healthcare providers, the consensus criteria were that the prioritized statements had to have a mean score of six and above and that they had not been rated below four on the seven Likert type scale. If the same criteria had been followed for this Q-Delphi study, 44 statements would have been ended as consensual. That was considered to be a large number and hence, a more strict approach was adopted. For the high priority statements to be consensual, they had to have a mean score of six and above and not been rated below five (medium high priority) on the seven Likert type scale, meaning that they would have a standard deviation below one. The same strategy was followed by Broomfield and Humphris (2001) in their Delphi study in identifying the cancer education requirements of general practitioners. Eighteen statements met these criteria and are presented in table 5.38. The statements are presented under the categories from which they originated and the number next to each category indicates the number of statements under this category.

Table 5.38 The consensual statements by healthcare users

Category (no of statements under category)	Statements	Mean score
Day units (2)	Day clinics should be developed, the existing beds are not enough.	6.38
Education / Training (11)	All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning.	6.75
	Doctors and nurses who work in special cancer centres should be properly educated.	6.58
Finance (2)	Free drug provision by all insurance companies.	6.54
New treatment (1)	New ways of treatment should be found, more effective.	6.63
Organisation (8)	Organised provision of cancer care services, so that cancer patients are not transferred from hospital to hospital for examinations and special treatments.	6.38
	Tests and in particular biopsies should be completed faster, giving priority to patients who need treatment faster.	6.42
	Better allocation of the CAT scans and all the special equipment and not consolidation in Athens and Thessaloniki.	6.63
Pain management (6)	The procedure of supplying opioid analgesics to patients must be improved.	6.25
Psychological support (11)	Psychological support for the patient and close relatives.	6.25
Resources (11)	First of all, there should be enough space, because it is not fair for 16 patients to be in the same room, and it is depressing for somebody at the beginning of the disease to watch somebody on the last stages.	6.58
	Improvement of the wards. Less beds in the rooms.	6.46
Special cancer units (7)	Appropriate places for chemotherapy treatment.	6.04
	Cancer centres should be built in the district, so that patients with special needs will not have to travel to Athens or Thessaloniki.	6.33
Staff shortages (5)	Specialised medical and nursing staff should be increased.	6.29
Staff skills (1)	Nurses should treat cancer patients like all the other patients, making them feel comfortable and forget their problem.	6.21
Technology (5)	Hospitals should provide the appropriate equipment and the appropriate specialised staff.	6.54
Extra beds (2)	They should not leave the patients in the corridors for hours or even days, having as result the physical and psychological exhaustion of the patients.	6.38

5.3 COLLECTIVE FINDINGS FROM HEALTHCARE PROVIDERS' AND HEALTHCARE USERS' RATINGS

The healthcare providers' panel generated 130 statements in round one that were grouped under 29 categories and healthcare users provided 123 statements that were grouped under 27 categories. The analysis of the first round and the creation of categories were performed by the same panel for both studies as described in chapters 5.1.1.1. and 5.2.1.1. Table 5.39 shows the categories for both groups and the number of statements under each category. The categories are presented in descending order according to the number of statements under each category.

Table 5.39 Categories and number of statements by healthcare providers and healthcare users

Healthcare providers		Healthcare users	
Categories	**No of statements**	**Categories**	**No of statements**
Home care	18	Resources	11
Education/Training	12	Psychological support	11
Public health/Health promotion	11	Education / Training	11
Psychological support	10	Information	11
Special cancer units	7	Organisation	8
Financial resources	6	Public health / Health promotion	8
Pain management	6	Special cancer units	7
Day units	5	Pain management	6
Hospices	5	Staff attitude	6
Research	5	Technology	5
Staff shortages	5	Home care	5
Communication	4	Staff shortages	5
Information	4	Communication	4
Health centres	3	Hospices	4
Hospital environment	3	Extra costs	3
Misc	3	Finance	2
Organisation	3	Day units	2
Prevention/Screening	3	Hospital environment	2
Support	3	Research	2
Technology	3	Extra beds	2
Cancer registration	2	Treatment	2
Hostels	2	Support	1
Education	1	Staff skills	1
Networking	1	Satisfaction	1
Occupational therapy	1	Networking	1
Special services	1	Stigma	1
Stigma	1	New treatment	1
Waiting lists	1		
Working conditions	1		
Total	**130**	**Total**	**123**

Eighteen categories were identical for both healthcare providers and users. For these categories, the responses were grouped and the number of times each category mentioned was observed. Some respondents mentioned a category more than once and therefore the total number of responses for each category was also calculated. In table 5.40, the same categories for both groups are presented in alphabetical order along with the number of each category mentioned by the participants and the number that each category was mentioned at least once by any of the participants.

Table 5.40 Categories that were identical for both healthcare providers and healthcare users

Healthcare providers			Categories	Healthcare users		
A	**B**	**Ratio**		**A**	**B**	**Ratio**
4	4	1.00	Communication	4	4	1.00
5	5	1.00	Day units	2	2	1.00
12	10	1.20	Education / Training	11	10	1.10
18	16	1.13	Home care	5	5	1.00
5	5	1.00	Hospices	4	4	1.00
3	3	1.00	Hospital environment	2	2	1.00
4	3	1.33	Information	11	10	1.10
1	1	1.00	Networking	1	1	1.00
3	3	1.00	Organisation	8	7	1.14
6	6	1.00	Pain management	6	6	1.00
10	9	1.11	Psychological support	11	11	1.00
11	9	1.22	Public health / Health promotion	8	7	1.14
5	4	1.25	Research	2	2	1.00
7	5	1.40	Special cancer units	7	5	1.40
5	4	1.25	Staff shortages	5	4	1.25
1	1	1.00	Stigma	1	1	1.00
3	3	1.00	Support	1	1	1.00
3	3	1.00	Technology	5	5	1.00

A: No of times each category was mentioned
B: No of respondents who mentioned each category once

In order to establish whether there was a significant difference between the responses of the two groups for these eighteen categories, three independent t-tests were used. However, no significant differences were found between healthcare providers and healthcare users for the:

- number of times each category was mentioned (t=0.508, d.f.=34, p=0.615);
- number of respondents who mentioned each category at least once (t=0.338, d.f.=34, p=0.738);
- ratio of the times each category was mentioned to the respondents who mentioned each category once (t=1.021, d.f.=34, p=0.315).

The average of the means for the statements under each of the 29 categories from the study of the healthcare providers and the 27 categories from the study of the healthcare users was computed and a mean score was appointed for each category. The categories were then ranked in order according to their mean score, as shown in table 5.41.

Table 5.41 The categories ranked in order based on the average of mean scores of the statements within each category

Healthcare providers Categories	Total mean	Rank	Healthcare users Categories	Total mean	Rank
Working conditions	6.77	1	New treatment	6.63	1
Communication	6.57	2	Extra beds	6.46	2
Education / Training	6.53	3	Research	6.42	3
Staff shortages	6.53	4	Treatment	6.35	4
Home care	6.51	5	Staff skills	6.21	5
Pain management	6.48	6	Reesources	6.16	6
Cancer registration	6.48	7	Financial resources	6.15	7
Day units	6.43	8	Organisation	6.11	8
Psychological support	6.43	9	Special cancer units	6.08	9
Prevention / Screening	6.38	10	Extra costs	6.07	10
Waiting lists	6.35	11	Hospices	6.05	11
Hospital environment	6.31	12	Staff shortages	6.03	12
Hostels	6.28	13	Day units	6.02	13
Financial resources	6.27	14	Pain management	6.01	14
Research	6.24	15	Home care	5.99	15
Hospices	6.22	16	Education / Training	5.92	16
Technology	6.20	17	Public health / Health promotion	5.92	17
Stigma	6.17	18	Technology	5.92	18
Networking	6.14	19	Staff attitude	5.87	19
Misc	6.14	20	Psychological support	5.79	20
Support	6.02	21	Stigma	5.79	21
Education	6	22	Information	5.63	22
Special cancer units	5.98	23	Hospital environment	5.6	23
Organisation	5.98	24	Communication	5.44	24
Public health / Health promotion	5.95	25	Support	5.29	25
Health centres	5.65	26	Networking	4.88	26
Special services	5.55	27	Satisfaction	3.96	27
Information	5.47	28			
Occupational therapy	4.95	29			

However, it was considered that the mean scores for each category did not project the variability in the ratings of the participants. Two statements may have the same mean score but different standard deviation. In such cases, it is natural that the statement with the smaller standard deviation is preferred. In a general sense, it is important that any combined average value would take this important preference into account. This can be achieved by introducing a weighting strategy based on the calculated variance of the individual mean values.

In that case, the weight of each mean value would be the inverse (reciprocal) of its variance divided by the total of the inverse variances for the complete group. For example, in the case of a group of three statements: m_1, v_1; m_2, v_2 and m_3, v_3

$$M \text{ (the total mean)} = \frac{\frac{1}{v_1} m_1 + \frac{1}{v_2} m_2 + \frac{1}{v_3} m_3}{\frac{1}{v_1} + \frac{1}{v_2} + \frac{1}{v_3}}$$

Table 5.42 shows the categories ranked in order according to their revised mean scores.

Table 5.42 The categories ranked in order based on the revised mean scores

Healthcare providers	Total mean	Rank	Healthcare users	Total mean	Rank
Categories			**Categories**		
Staff shortages	6.88	1	New treatment	6.63	1
Working conditions	6.77	2	Treatment	6.45	2
Pain management	6.71	3	Research	6.42	3
Day units	6.70	4	Extra costs	6.34	4
Communication	6.68	5	Finance	6.33	5
Home care	6.68	6	Organisation	6.31	6
Prevention / Screening	6.66	7	Extra beds	6.30	7
Psychological support	6.61	8	Education / Training	6.29	8
Cancer registration	6.60	9	Resources	6.24	9
Education / Training	6.60	10	Staff skills	6.21	10
Financial resources	6.44	11	Day units	6.17	11
Hospices	6.36	12	Special cancer units	6.15	12
Waiting lists	6.35	13	Hospices	6.13	13
Hospital environment	6.32	14	Technology	6.13	14
Special cancer units	6.32	15	Staff shortages	6.13	15
Hostels	6.30	16	Pain management	6.06	16
Research	6.28	17	Home care	6.05	17
Technology	6.18	18	Staff attitude	5.96	18
Stigma	6.17	19	Public health / Health promotion	5.95	19
Networking	6.14	20	Psychological support	5.87	20
Public health/Health promotion	6.11	21	Stigma	5.79	21
Misc	6.07	22	Hospital environment	5.67	22
Support	6.05	23	Information	5.65	23
Organisation	6.04	24	Communication	5.50	24
Education	6.00	25	Support	5.29	25
Information	5.81	26	Networking	4.88	26
Health centres	5.81	27	Satisfaction	3.96	27
Special services	5.55	28			
Occupational therapy	4.95	29			

For the 18 categories shared by healthcare providers and users, the average precise score was computed and the categories are presented ranked in order based on the healthcare providers' priorities in table 5.43. The table also shows the difference between the mean scores for the two groups.

Table 5.43 Healthcare providers' and users' shared categories ranked in order based on their precise mean scores

Healthcare providers		Categories	Healthcare users		Difference between mean scores
Mean	Rank		Mean	Rank	
6.88	1	Staff shortages	6.13	7	0.75
6.71	2	Pain management	6.06	9	0.65
6.7	3	Day units	6.17	4	0.53
6.68	4	Communication	5.5	16	1.18
6.68	5	Home care	6.05	10	0.63
6.61	6	Psychological support	5.87	12	0.74
6.6	7	Education / Training	6.29	3	0.31
6.36	8	Hospices	6.13	6	0.23
6.32	9	Hospital environment	5.67	14	0.65
6.32	10	Special cancer units	6.15	5	0.17
6.28	11	Research	6.42	1	-0.14
6.18	12	Technology	6.13	8	0.05
6.17	13	Stigma	5.79	13	0.38
6.14	14	Networking	4.88	18	1.26
6.11	15	Public health / Health promotion	5.95	11	0.16
6.05	16	Support	5.29	17	0.76
6.04	17	Organisation	6.31	2	-0.27
5.81	18	Information	5.65	15	0.16

The mean difference for the scores between healthcare providers and users is 0.46 with 95% CI (0.25, 0.66). This implies that either the providers were providing consistently high ratings for the statements or the users were providing lower ratings. It is interesting to note that only for two of the categories (research and organisation) the scenario was reversed.

An independent *t*-test was performed to establish whether there was a significant difference between the mean scores for the categories for the two groups. As it was anticipated, a significant difference was found for the mean scores of the

categories for the two groups (t=3.909, d.f.=34, p<0.001), showing that healthcare providers and healthcare users prioritised the categories differently under investigation. There was a weak association for healthcare providers' and users' categories ranking, however it was not significant (Kendall's tau-b= 0.147, N=17, p=0.41).

5.4 SUMMARY OF FINDINGS

In summarising the findings of the two Q-Delphi studies, it was revealed that the highest prioritised categories identified by healthcare providers focused on working conditions and staff shortages. Healthcare providers also highly rated issues such as pain management, the creation of day units and communication. Furthermore, priority was given to home care, prevention, psychological support to patients and the education of health professionals. An important issue such as the creation of a national cancer registration was also regarded as a high priority among healthcare providers. It was also revealed that there was a significant agreement on the ratings among the groups of doctors, nurses and the remaining healthcare providers in the second round.

In the third round, the healthcare providers' consensual priorities focused on the shortage of specialised nursing personnel, the operation of oncology hospitals, the development of all types of acceptable special services in these hospitals and the role of the media in cancer prevention. There was also agreement on the creation of accessible specialised services in different parts of Greece so that cancer patients would not have to travel far for treatment. Healthcare providers agreed on the need for better education on every educational level, especially on communication skills. Consideration was also given and consensus was achieved for the need of psychological support for cancer patients and the need for palliative care either at home or in special institutions. A significant agreement was revealed on the rankings within the group of doctors, nurses and the remaining healthcare providers.

In the second round of the healthcare users, the prioritised categories were focused on effective treatment and research in discovering more effective treatments. Priority was also given to the organisation of cancer care and the financial support that cancer patients should receive if they have to pay for special tests and treatment. The education of health professionals was also highly prioritised, particularly with regards to the development of healthcare professionals' skills.

Agreement was achieved in the area of health professionals' education so that they are better able to understand and diagnose the early signs of cancer. Under the category 'organisation', statements which reached consensus suggested better allocation of special equipment so that cancer patients do not have to be transferred for special examinations, and the faster completion of biopsies. Agreement was achieved in issues such as the increment of specialised healthcare personnel and the number of beds for cancer patients. Healthcare users agreed on the priority of psychological support not only for cancer patients but also for their relatives, as well as the improvement in the supply of opioid analgesics.

When the results from both Delphi studies were compared, based on the categories that both healthcare providers and healthcare users shared, it was revealed that their prioritisation was significantly different.

In the next chapter, the discussion is presented in which the main findings are explained using the conceptual framework that was established based on WHO recommendations for controlling cancer.

CHAPTER SIX

6. DISCUSSION

Rudestam and Newton (2001) maintain that the discussion chapter provides researchers with an opportunity to move beyond the data and to weave creatively the results of their study with the existing research. This chapter discusses the main findings obtained from the examination of the data from two Q-Delphi studies of healthcare providers and healthcare users respectively. The aim was to identify elements/statements that should be given high priority in the area of cancer care to improve cancer care services in Greece. To this end, the theoretical framework derived from the World Health Organisation's (2002) strategies and recommendations will be used as a yardstick to compare and discuss the current research findings.

The World Health Organisation is regarded as the leading international agency in health. Despite the high reputation of the organisation in the 1970s with the 'Health for All by the Year 2000' recommendations and the successful world wide eradication of smallpox, the 1980s and 1990s saw WHO losing much of its authority (Horton 2002). The debate has focused mainly on whether WHO should set standards, develop guidelines and provide information that can be used by governments when implementing their own programmes or whether WHO should also be involved in implementing their programmes (McCarthy 2002). The WHO guidelines for controlling cancer as considered normative and reliable are used to discuss the results of this study. WHO remains the leading source of information, setting standards and creating manuals for infectious and non-infectious diseases surveillance, prevention and control world wide (McCarthy 2002).

Another approach for the current study could have been the use of the WHO (2002) guidelines to develop a questionnaire and request healthcare providers and users to prioritise the issues raised by WHO. However, such an approach would have limited the freedom of participants to express their views. Participants would have only considered and prioritised what would have been indicated by WHO. The developed priorities would have not entirely reflected the participants' views. In addition, it was

anticipated that healthcare users might have not been able to comprehend the WHO guidelines that form a policy document, resulting in misapprehension and difficulties in identifying priorities. With the Delphi technique, as it was adopted for the current study, the participants were more active in creating the suggestions about the development and improvement of cancer care services in Greece themselves and furthermore agreeing on their prioritisation. Following this approach, the local peoples' needs were acknowledged and there were no views imposed on them. The guidelines by WHO (2002) that are going to be used in this chapter may help to compare and validate the priorities set by the healthcare providers and users in the current study. In addition, if the priorities provided by healthcare providers and users were found to be analogous to those stated within the WHO guidelines, they would further enhance the credibility of the latter. In that case, the WHO guidelines for decreasing the burden of cancer in the community could be seriously considered by policy makers when taking decisions about cancer care services.

As a basis for discussing the findings, the categories and their prioritisation from the second round for both groups will be compared and linked with the suggestions made within the WHO (2002) framework. Where appropriate, the suggestions from the healthcare providers' third round Q-Delphi ranked in order (Table 5.16 to Table 5.24) will also be compared with the WHO (2002) guidelines. Finally, the consensual suggestions as well as the differences for both groups will be discussed based on the WHO framework.

6.1 THE 'IDEAL TYPE' SCENARIO FOR GREECE

WHO (2002) suggests that national cancer control programmes should be developed by all countries to ensure effective, efficient and equitable use of existing resources. Although Greece is considered a 'high income' country, the resources available for cancer care are those of a 'middle income' country. Human and financial resources are limited in Greece for the healthcare sector. According to healthcare providers in this study, the first issue that should be given priority was the problem of staff shortages. This was the first prioritised category in round two. Taking into account the ranking of statements under the category of 'manpower resources' in round three among healthcare providers, the problem of staff shortages was focused on nursing personnel. The following statement was ranked first by 42.3% of the healthcare providers in the third round:

> *"The shortage of specialised nursing staff requires the immediate initiation and application of a plan for the recruitment and retaining of nurses in the profession".*

The problem of nursing shortages in Greece has been well documented. Plati *et al.* (1998) have reported that the number of nursing personnel was 35,715 in 1993 while the estimated needs were 62,000. Polyzos and Yfantopoulos (2000) also reported on the shortages of the nursing personnel in their paper adding that before or after graduation, 50% of nurses leave the profession due to unacceptable working conditions. Another study by Andrioti *et al.* (1994) using a questionnaire approach revealed that 23% of nurses (n=113) suggested increasing the nursing personnel in order for the hospitals to operate more efficiently. In addition, a more recent study among 800 health professionals and administrative staff working in public hospitals suggested that for 25% of the nurses in the sample, the shortage of nursing personnel was a major problem for the Greek NHS (Komninou 2000).

However, it should be noted that the problem of staff shortages was not among the first ten priorities of healthcare users in this study. As a category, it only reached the 15th place in round two. The statement that met the criteria of consensus among this group focused on increasing both medical and nursing personnel:

> *"Specialised medical and nursing staff should be increased".*

It is possible that healthcare users do not realise the problem of human resources shortages, especially nursing personnel, as during hospitalisation most of the patients tend to have a close relative offering personal care which could be considered as part of the nursing role. It should be considered that every patient and family bring with them cultural norms. It is important to mention the close bonds found in Greek families, especially towards severe problems such as cancer (Mystakidou *et al.* 2002, Iconomou *et al.* 2001). In addition, Merkouris *et al.* (1999), in a study of 103 patients in a Greek teaching hospital, revealed that most of the patients (70.9%) were satisfied with the nursing care. However, a large percentage of these patients (68.5%) also stated that they were assisted by relatives or private nurses and 31.6% of the sample mentioned staff shortages as a major concern.

One of the suggestions by WHO (2002) for national cancer control programmes to work is the development of education and continuing training for healthcare workers. In this study, education and training for health professionals was ranked 10th by healthcare providers and eighth by healthcare users. Healthcare providers, under this category and in the third round, ranked a statement that suggested improvement in all levels of education for all healthcare professionals first:

> *"Education (basic, post-basic and continuing) must be improved for all health professionals (doctors, nurses, psychologists, social workers)".*

Healthcare users rated a statement that addressed the issue of education higher so that healthcare professionals are aware of early signs of cancer:

> *"All the doctors should be aware of the cancer symptoms, in order to diagnose cancer early, at its beginning".*

It is possible that education and continuing training are not amongst the highest priorities for participants in this study as they assume that healthcare professionals already have a reasonable level of education and it should therefore not be prioritised. In a study among 256 Greek medical students, the importance of training in oncology was also addressed. However, the level of oncology education was considered average by 46% of the students with a majority believing that oncology should be taught as an independent module (Andrikopoulos *et al.* 1999). For healthcare users, the clinical

skills of the health professionals were considered important and were ranked 10th. In a Finish study of 168 carers of cancer patients, professional skills were also identified by all as very important (Erikson and Lauri 2000). In a post-bereavement study by Rogers *et al.* (2000), it was also established that, despite the complaints about medical and nursing staff by the participants, none of them related to the competence of healthcare professionals. However, in the same study education and training were highly prioritised.

One of the issues raised by health professionals in the current study, regarding education was that of training in communication skills. In Mystakidou *et al.*'s (1996) study among 228 Greek oncologists, radiotherapists and palliative care specialists, it was revealed that 39% of the sample felt that they were not adequately trained in communication skills. Communication was an issue raised by both healthcare providers and users in this research. Participants from both panels suggested that the breaking of bad news should be communicated sensitively and there should be appropriate training provided for healthcare professionals for this purpose. This category was ranked fifth among the group of healthcare providers. A study by Wells *et al.* (2001) of 135 medical and nursing staff also supports that teaching skills on breaking bad news should be a priority in education. All statements under the category of 'communication' met the consensus criteria for healthcare providers. In the third round, and under the same category, 65.4% of the healthcare providers ranked the need for special training in communication skills as first.

Communication and information are very important issues in the healthcare area, especially if patients have to remain autonomous and make decisions about their health and participate in decision making for the development and improvement of cancer services. However, communication received low rating by healthcare users and it was placed at the 24th place. In addition, none of the statements under this category met the consensus criteria in the study with the healthcare users. In other studies, training in communication skills for health professionals among patients and carers was regarded as very important. For example, in the study by the National Cancer Alliance (1996), health professional's training in communication skills was regarded as very important by 90% of the patients and carers.

Communication between patients and health professionals, especially in disclosing a cancer diagnosis is an important issue in Greece. Even the most recent studies reveal that cancer patients are not aware of their diagnosis with reports ranging from 59% to 78%, depending on the setting where the research was performed (Mystakidou *et al.* 1996, Iconomou *et al.* 2002). Patients depend on their physicians to be informed and research has shown that Greek patients are not satisfied with the information they receive in general hospitals (Merkouris *et al.* 1999). On the contrary, 77 out of 100 chemotherapy outpatients in a Greek university hospital of whom only 41 were aware of their cancer diagnosis expressed their satisfaction with the information they had received (Iconomou *et al.* 2002). However, within this group, 80% expressed the need for extra information in the form of a booklet. In a British study, all cancer patients (n=72) regarded information issues as very important (NCA 1996). Erikson and Lauri (2000) have also suggested that for all of the 168 carers of cancer patients in their study, medical and nursing information was very important. In the current study, it is likely that healthcare users were satisfied with the information they had received and this category was ranked only 23rd. It should be considered that cancer patients in the current study were aware of their diagnosis and had probably received adequate information about their situation. However, the study by Iconomou *et al.* (2002) showed that awareness of diagnosis was independent of satisfaction with information received.

Further research needs to be carried out on the willingness of Greek patients to be fully informed of their diagnosis and prognosis. In addition, evidence is needed on the effectiveness of communication skills training courses as research has shown that they do not produce the expected outcomes (Shilling *et al.* 2003). It is anticipated that with the appropriate communication skills, healthcare professionals will be able to identify the patients' individual needs for information and act accordingly. Overall, the need for research and training in communication skills remains

According to the WHO (2002) framework, in order to control the burden of cancer in the community, action should be taken in four areas: prevention, early diagnosis, therapy and palliative care. The following sections discuss the results of this study based on the recommendations by WHO (2002) for middle income countries.

6.1.1 Prevention

Prevention means eliminating or minimizing exposure to the causes of cancer, and includes reducing individual susceptibility to the effects of such causes. This approach may offer the greatest public health potential and the most cost effective long-term cancer control (WHO 2002). One of the areas suggested by WHO (2002) for action to be taken by national cancer control programmes is that of prevention. Health promotion strategies for non-communicable diseases include legislative and environmental measures as well as educating the general public. Table 6.1 shows the 'ideal type' suggestions for the medium level scenario and the consensual statements from the current study for the prevention category:

Table 6.1 WHO recommendations and the results from the current study on the area of prevention

WHO Medium Level Scenario	Current Study
▪ Develop integrated clinical preventive services for counselling on risk factors in primary healthcare settings, schools and workplaces ▪ Develop model community programmes for an integrated approach to prevention of non-communicable diseases	▪ "Media should inform people about cancer prevention" HCP* ▪ "Cancer prevention programmes must be developed with the co-operation of all health professionals" HCP*

*Healthcare Providers

The 'health promotion' category was placed as the 21st and 19th priority for healthcare providers and healthcare users respectively in the second round of the Q-Delphi studies.

Under this category, healthcare providers focused on the role of the media in promoting cancer prevention. The media's contribution to cancer prevention may be invaluable, however Marino and Gerlach (1999), after an examination of seven American popular magazines for seven years, revealed that screening guidelines were recommended in 68% of the articles that discussed prevention and concluded that magazine reports may well be contributing to women's misunderstanding of their true cancer risk. For the healthcare users' panel, the focus was on informing women with leaflets or through the media to be examined for breast or cervical cancer. Yet none of the statements under this category reached consensus for the panel of healthcare users.

WHO (2002) also emphasises counselling on risk factors in primary healthcare settings, schools and workplaces for countries in the middle scenario. Under the category of health promotion, one statement by healthcare providers indicated the organisation of seminars about risk factors at schools and municipalities, however a consensus was not reached on this statement.

With regards to the panel of healthcare users, it is possible that they did not rate health promotion activities highly given that they were already cancer patients or carers involved in the care of a cancer patient and health promotion issues were not considered important at that stage. However, it was expected that carers would prioritise the area of prevention as healthy individuals. It has to be considered that the entire health system in Greece is treatment orientated and health promotion has not been emphasised (Petridou *et al.* 1999). On a positive note, it should be noted that healthcare providers suggested the integration of all health professionals' knowledge in the development of cancer prevention programmes.

6.1.2 Early Diagnosis

Early detection comprises early diagnosis in symptomatic populations and screening in asymptomatic, but at risk, populations. Increasing awareness of the signs and symptoms of cancer contributes to detection of the disease in its early stages. With early detection, there is a greater chance that curative treatment will be effective (WHO 2002). This area has also been stipulated as an area of care warranting promotion. It is indicated that countries in the medium level should promote early diagnosis through awareness of

early signs and symptoms of detectable and curable cancers such as breast and cervical cancer (WHO 2002). Table 6.2 shows the 'ideal type' suggestions for the medium level scenario and the consensual statements from the current study for the area of early diagnosis:

Table 6.2 WHO recommendations and the results from the current study on the area of early diagnosis

WHO Medium Level Scenario	Current Study
▪ Use low cost and effective community approaches to promote early diagnosis of all priority detectable tumours ▪ Provide national coverage cytology screening for cervical cancer at 5 year intervals to women aged 30 to 60 years	▪ "All the doctors should be aware of the cancer symptoms, in order to diagnose cancer early, at its beginning" HCU** ▪ "Screening services in hospitals should be working more hours, so that waiting lists may get shorter" HCP*

* Healthcare Providers

** Healthcare Users

Healthcare users rated a similar statement to the one suggested by WHO (2002) highest:

> *"All the doctors should be aware of the cancer symptoms, in order to diagnose cancer early, at its beginning".*

Among this group, the notion of doctors being aware of early symptoms in order to diagnose cancer early was agreed as the highest priority. It is surprising that healthcare providers did not mention early diagnosis in this study.

For the middle scenario proposed by WHO (2002), emphasis is also given to the area of screening. Countries in scenario B are advised to implement screening for cervical cancer on a national level at five year intervals to women aged 30 to 60 years. Screening as a theme was identified after the content analysis of the statements provided by healthcare providers. It was also ranked seventh as a category among the same group. One of the highest rated statements within this category, in the second round, suggested well organised screening programmes for the population, such as Papanikolaou (PAP) test or mammographies, and not sporadically as is the case

currently. This statement was rated as a low priority by one participant and did not meet the consensus criteria for the healthcare providers to be involved in round three. The statement that did meet the consensus criteria and ranked third among the three statements of the category 'prevention' in the third round of healthcare providers indicated the extension of working hours in hospitals' screening services.

By contrast, healthcare users did not provide any statements on screening. As no cancer screening programme is provided on a national level, the efficacy of screening has not been demonstrated in Greece. It is possible that the Greek population is not aware that early detection of many cancers may lead to improved long-term survival rates.

6.1.3 Treatment

Cancer diagnosis is the first step to cancer management. Once a diagnosis is confirmed and cancer staging is ascertained, the next step is treatment. The primary objectives of cancer treatment are cure, prolongation of life, and improvement of the quality of life. A national cancer control programme should establish guidelines for integrating treatment resources with programmes for early detection and provide therapeutic standards for the most important cancers (WHO 2002). The standard for the medium level scenario should be the organisation of diagnosis and treatment services giving priority to early detectable cancers or to those with high potential of curability (WHO 2002). Table 6.3 shows the 'ideal type' suggestions for the medium level scenario and the consensual statements from the current study for the area of treatment:

Table 6.3 WHO recommendations and the results from the current study on the area of treatment

WHO Medium Level Scenario	Current Study
▪ Organise diagnosis and treatment services, giving priority to early detectable tumours or to those with high potential of curabililty	▪ "New ways of treatment should be found, more effective" HCU** ▪ "Organised provision of cancer care services, so that cancer patients are not transferred from hospital to hospital for examinations and special treatments" HCU**

** Healthcare Users

Organisation of diagnosis and treatment was highly rated by healthcare users compared to that of healthcare providers in this study. The category 'organisation' which included items regarding the organisation of diagnosis and treatment was ranked sixth among healthcare users. Three statements reached consensus in the second round for healthcare users which indicated that patients should not have to complete tests in different places and that test results should be completed and communicated more efficiently. Healthcare users stressed the need for cancer care to be offered in one place.

Taking into account the ranked categories in the second round for healthcare users, their first two prioritised categories were 'new treatment' and 'treatment'. The statement implying effective new treatment for cancer patients reached consensus among this group. Even the third ranked category, 'research', among this group suggested research in improving treatment and the side effects of treatments. The treatment received by the 72 cancer patients in a British focus group was also regarded as a priority (National Cancer Alliance 1996).

Research as a category among healthcare providers was not ranked highly. This is of concern particularly as there is an increasing move towards evidence-based practice in

many countries (Department of Health 1999). With regards to nursing practice in the UK, the Nursing and Midwifery Council (NMC) places great importance on keeping up to date and basing practice on evidence (NMC 2002). However, research in nursing has not been prioritised by the healthcare providers in the current study. Research has also received low priority among nurses in the studies conducted by Twycross (1999, 2001). This could be attributed to clinical skills being more important for nurses as opposed to theoretical knowledge (NMC 2002).

The benefits of specialist cancer care are well recognised. Campbell *et al.* (1999) indicated that patients cared for by specialists have been reported to receive more up to date treatment and have improved chances of survival. Centralisation of services has advantages, however there are disadvantages for patients in remote areas who would have difficulty in accessing these services. Due to the geographical particularities of Greece, centralisation of services might pose problems for patients in accessing high quality services. In this study, both groups generated statements that suggested the development of special cancer units and cancer centres. This category in the second round was ranked 15th among healthcare providers and 12th among healthcare users. One of the problems associated with centralised services is that of the uptake of treatment for patients who need to travel longer distances. Three statements were generated by healthcare users in round one under the category 'special cancer units' that suggested the creation of units in district hospitals to improve accessibility of services. However, none of the statements in this category met the consensus criteria established for the two groups in the second round.

6.1.4 Palliative Care

Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. Improved quality of life is of paramount importance to patients with cancer (WHO 2002). Palliative care has been given great attention by WHO, especially for developing countries where 80% to 90% of patients are incurable at diagnosis (Coyne 1997). It is well recognised that the principles of palliative care should be applied as early as possible (Sepulveda *et al.* 2002). The fourth area that WHO (2002) advises action to be

taken on is pain relief and palliative care. All countries should implement comprehensive palliative care that provides pain relief, other symptom control, and psycho-social and spiritual support. Table 6.4 shows the 'ideal type' suggestions for the medium level scenario and the consensual statements from the current study for the area of palliative care:

Table 6.4 WHO recommendations and the results from the current study on the area of palliative care

WHO Medium Level Scenario	Current Study
▪ Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care and nation-wide there is rising coverage of patients through services provided by primary healthcare clinics and home-based care	▪ "Development of terminal care for the patients either at home or in special hospitals and institutions" HCP* ▪ "Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics." HCP* ▪ "Psychological support groups must be created in oncology hospitals consisting of psychiatrist, nurses, psychologist and social workers" HCP* ▪ "The procedure of supplying opioid analgesics to patients must be improved" HCU** ▪ "Psychological support for the patient and close relatives" HCU**

* Healthcare Professionals

** Healthcare Users

Pain management as a category was indicated by both groups. Healthcare providers rated suggestions under this category highly and it was ranked third among the categories for this group. The category 'palliative care / pain management' with three statements that met the consensus criteria appeared in the third round questionnaire of

healthcare providers, which asked the participants to rank the three statements. The statement that suggested the development of palliative care either at home or in special institutions under this category, was ranked first by 46.2% of the participants in third round. The second statement addressed the problem of pain management and the development of pain clinics. Thirty eight percent of the participants ranked this statement as the second priority. By contrast, a Norwegian study among 199 oncology nurses revealed that pain control and management were not among their most important priorities (Rustoen *et al.* 2003).

For the healthcare users in round two 'pain management', as a category, reached the 16th position. Only one statement under this category was consensual and it suggested improvements in the procedures of supplying opioid analgesics. This is one of the recommendations by WHO (2002) for all countries regardless of the level of resources, advice and accessibility of opioids available. It was surprising that the issue of pain management was not ranked higher by healthcare users as cancer pain is reported by almost 50% of patients at all stages of disease and by over 70% of patients with advanced neoplasms (Higginson and Hearn 1997). Little evidence from Greece shows that pain is evident and unrelieved (Mystakidou *et al.* 1999). Pain control is far from optimal even for patients receiving specialist palliative care (Table 2.1). It is anticipated that cancer patients and their carers may perceive physical problems, such as pain, an inevitable part of the disease and treatment and this is possibly why they do not considered pain control as a priority issue (Newell *et al.* 1998).

Hospices are the places where specialist palliative care is usually offered. Both groups in this research provided statements regarding the development of hospices and as a category it was ranked 12th among healthcare providers and 13th among healthcare users in the second round. None of the statements under this category met the consensus criteria. The first hospices operating in Greece during the 1960s were closed as it was considered that they did not serve the palliative purposes for which they were built. It is not surprising that the hospice movement has yet to be developed in Greece.

One of the elements of palliative care is psychological support. Both groups in the Q-Delphi studies provided statements for psychological support and a category was created. This category was ranked eighth among healthcare providers. For the

healthcare providers, five statements under this category met the consensus criteria and formed a category for the third round where participants were asked to rank them in order of priority. Almost half of the participants highly ranked a statement which suggested the creation of psychological support groups in oncology hospitals, consisting of a range of healthcare professionals:

> *"Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist, social workers etc.".*

Psychological support for cancer patients was also considered important in a Norwegian study where half of the nurses (n=199) reported cancer patients' anxiety as a problem in clinical practice and stressed the need for psychological support (Rustoen *et al.* 2003). However, for the healthcare users psychological support was ranked 20th. The statement that met the consensus criteria among the group of healthcare users indicated the need for psychological support for the patients and close relatives:

> *"Psychological support for the patient and close relatives".*

It was surprising that healthcare users did not highly rate statements suggesting psychological support in this study. It is possible that due to the strong links among families in Greece, psychological problems are usually resolved within the family (Iconomou *et al.* 2001). In addition, a Greek study among 146 relatives of cancer patients revealed that 22% of the participants would not like to liaise with psychological support specialists (Mystakidou *et al.* 2002). However, in a Finnish study among 168 carers of cancer patients, psychological support was regarded as important by half of the participants and only a small percentage (8%) had received much support by health professionals (Eriksson and Lauri 2000). The difference in ranking psychological support between healthcare providers and users could also be attributed to the existing trend by health professionals to rate the emotional and psychological aspects of caring higher than cancer patients (Larsson *et al.* 1998). In a study by Newell *et al.* (1998), it was revealed that oncologists perceived much higher levels of depression and psychological problems for the patients they treated than the patients perceived themselves.

Within the medium level scenario, one of the recommendations by WHO (2002) for the area of palliative care, is for countries to ensure continuity of care for patients through services provided by primary healthcare and home-based care. Among healthcare providers, there was one statement rated as very high priority by all participants in round two. That statement suggested the development of home care for cancer patients during treatment and at the end of life:

> *"Home care should be developed for oncology patients not only during treatment but for terminally ill patients too".*

Home care is very limited in Greece, whereas in the rest of the world there has been a shift towards developing more home care services (Kerkstra and Hutten 1996). These services are considered to be more cost effective (Rubenstein 1994), as well as being more consumer orientated (Sitzia and Wood 1997). The limited available studies in the area of home care in Greece have also revealed the cost effectiveness of the services (Tsitoura 1997) and the satisfaction of the patients (Christopoulou 1990).

Home care as a category was ranked sixth for the group of healthcare providers while for healthcare users it was surprisingly ranked 17th. For healthcare users, none of the statements under this category met the consensus criteria. The category 'home care' with the category 'day units' formed the category 'services development' for round three in the healthcare providers' Q-Delphi study. The statement ranked first within this group in round three suggested the development of day units and home care by all the oncology hospitals. Healthcare users focused more on day units and one of the statements from this group reached consensus which indicated the development of day units. Day units as a category was ranked fourth in the providers' group and 11th by the users. It seems that healthcare providers in Greece are more knowledgeable regarding the advantages of home care and this was the reason why it was ranked highly among this group. As home care services are underdeveloped in Greece, there seems to be a lack of patient and family knowledge in this area and this is possibly why home care was not ranked higher. Another possible reason could be that even where home care services exist, some patients are reluctant to let a stranger into their home, preferring assistance from family members. In addition, healthcare users may consider receiving cancer treatment at home unsafe (Christopoulou 1990).

WHO (2002) suggests that in the medium level scenario, some of the infrastructure may already exist but not very well organised. One of the issues that healthcare providers agreed on was in prioritising the organisation of cancer hospitals. The statement emphasising the independence and the efficiency that cancer hospitals should have was ranked first in the third round among this group under the 'organisation' category:

> *"Oncology hospitals must become independent, functional, efficient, non bureaucratic and human. The environment of oncology hospitals should not seem impersonal".*

This suggestion was ranked first by 61.5% of the healthcare providers. The organisation of oncology hospitals in Greece has also been an issue in other Greek studies. A study involving 800 health professionals' and administrative staffs' views about the Greek NHS (Komninou 2000) revealed that for 40% of the doctors in the sample, the bureaucracy existing in Greek hospitals is a major problem while only 8.9% of nurses in the sample shared the same view. An earlier study by Kyriopoulos *et al.* (1994) reported that 21.2% of 194 doctors suggested changes in the way hospitals were operating in order to become more efficient.

WHO (2002) also suggests that countries in all the scenarios have to establish a mechanism to monitor and evaluate outcomes of service provision. One of the ways to evaluate outcomes is through the reports of national cancer registrations. Among healthcare providers, the category 'registration' was ranked ninth. The statement for the development of a national cancer registration met the consensus criteria in the second round. Vlachonikolis *et al.* (1998) have reported the absence of a Greek national cancer registration, however they report an effort by their team to establish a cancer registry in Crete. Cancer registration programmes provide complete, accurate and timely data that can describe the state of the incidence of cancer at district, regional and national levels (International Agency for Research in Cancer 1999).

Table 6.5 presents the highest rated statements generated by both healthcare providers and users. They are listed beside the areas that were suggested by WHO (2002) for action to be taken on, in order to control the burden of cancer as indicated in chapter 4.2 The suggestions by WHO (2002) differ for countries with different levels of resources available for healthcare. Based on the three scenarios (A,B,C) for countries with low,

medium and high level resources respectively (Appendix 13), the statements are allocated under their relevant scenario. This would help to identify Greece's position with regards to the scenarios set by WHO from the participants' point of view. The table shows that the majority of statements were relevant to scenario B confirming the researcher's initial decision to view Greece under the medium level scenario.

Table 6.5 Healthcare providers' and users' views allocated under the WHO scenarios

	Healthcare providers	Scenario	Healthcare users	Scenario
Prevention	Seminars on cancer prevention should be organised at schools, municipalities, etc.	B	Prevention, which is the most important. They should urge women with leaflets to get examined in time	B
	Media should provide information to people on cancer prevention	B	The area of public information regarding high risk groups, causes and early signs of cancer, needs to be improved	B
	Cancer prevention programmes should be developed with the co-operation of all health professionals	C	Public education and sensitisation for routinely check ups at appropriate centres (like breast clinics) from the media	B
Early diagnosis and Screening	Well organised screening programmes should exist for the population, like PAP test or mammography, and not occasionally as it is nowadays	C	General doctors should be properly educated so that they can recognise the first symptoms of cancer	C
	Screening services in hospitals should be operating for more hours, so that waiting lists get shorter (waiting period for a mammography may take 4 months)	B	All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning	C
Curative therapy	Development of tertiary oncology care in large district hospitals	B	Better management of the treatment's side effects	B
			Tests and in particular biopsies should be completed faster, giving priority to patients who need treatment faster	B
Pain relief and palliative care	Greater attention should be given to the management of pain. Health professionals should be informed and educated on pain management. Pain clinics	B	The procedure of supplying opioid analgesics to patients must be improved	B
	Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life	B	Expansion of home care so that patients may die in their known environment, with dignity and the love of their relatives	B
	Nursing care for terminally ill patients should be provided in special nursing homes so that patients get special care	B	There should be special places for patients who are in the final stages of the disease, who need special care	B
	Psychological support should be provided to cancer patients and their families through all the stages of the disease	B	Psychological support for the patient and close relatives	B

Scenario A: Low level of resources; **Scenario B**: Medium level of resources; **Scenario C**: High level of resources

The above table (6.5) shows that healthcare providers and users placed most of their priorities within the medium level scenario. It is worth noting that none of the statements by the participants came under scenario A. This may indicate that the existing services are at most within scenario A. A validation of this assumption would require observing the 'true' level services provided in any of the specific areas of cancer care. This is a research project on its own which was out of the scope of this thesis.

Participants in the current study did not seem to have overestimated the level of resources available for healthcare and their suggestions were mostly under the suggested level for Greece. It was only on areas such as early diagnosis, that healthcare users placed their priorities on scenario C. At this level, the establishment of strategies is recommended for early diagnosis of all highly prevalent detectable cancers. It could possibly be that in the panel of healthcare users, cancer was not detected at an early stage and this could be the reason for suggesting this area to be listed under scenario C. In addition, healthcare providers in the area of screening, prioritised both cervical and breast cancer screening which are recommended for scenario C. Healthcare providers in the current study showed an awareness of the effectiveness of screening for cancer. However, they failed to realise the financial implications involved in establishing national screening programmes and the lack of official national cancer incidence rates that might not justify any form of cancer screening in Greece.

Overall, the conceptual framework drawn from the WHO (2002) recommendations on establishing national cancer control programmes, with suggestions for countries with different level of resources, proved to accommodate the views from both healthcare providers and users in this study. The allocation of Greece in Scenario B was also justified as the views of the participants fell mostly with this level. The results from the current study and the suggestions from scenario B will help to shape the recommendations for establishing effective cancer care services in Greece.

6.2 POLICY MAKING AND INVOLVING HEALTHCARE USERS IN THE PLANNING AND DEVELOPMENT OF CANCER SERVICES

In the area of policy making, issues usually become defined as problems when indicators, events or feedback force them onto the public agenda (Kingdon 1997). In the area of cancer care, indicators such as cancer incidence and mortality for Greece are estimated below the average rates in the European Union (Bray *et al.*2002). However, there exists a general dissatisfaction with the provision of services by the Greeek NHS which has forced several healthcare issues onto the public agenda to be considered. The dissatisfaction in the area of cancer care services was reflected in the current study by both healthcare providers and users.

After the completion of the second round questionnaires by healthcare providers and healthcare users, the mean scores were calculated for each statement. For the healthcare users' panel, it was found that 79% of the statements had a mean score of six and above on the seven point Likert type scale expressing the participants' view that most of the statements were of high priority. The high percentage raised concerns over the ability of the participants to discriminate between the statements. This was not the case for healthcare providers given that some suggestions received lower ratings. It is possible that the high ratings were an indication that healthcare providers were not satisfied with the existing services in the area of cancer care. A similar result was observed with the healthcare users' ratings in the second round questionnaire. Half of the statements had a mean score of six and above from a maximum of seven. The percentage of the statements rated highly may have been lower for healthcare users, however the dissatisfaction of this group with cancer care service provision is also highlighted. Indeed, the only statement that indicated satisfaction with cancer care services within this group was rated lower than any other statement, with a mean score of 3.96:

"My views regarding the staff and the place of treatment are positive"

Although this study was not a satisfaction survey, the problem of dissatisfaction with health services in Greece is well documented. A study conducted for the Ministry of Health in 1999 based on a sample of 5,800 patients, health professionals and citizens

revealed that only 29% of the sample were satisfied with the Greek health system while 68.5% of the sample were 'little' or 'completely' dissatisfied (Komninou 2000). The same level of dissatisfaction is reported in previous studies by the European Union (Ferrera 1993, EUROSTAT 2000).

The existing evidence shows that there is dissatisfaction with healthcare in general in Greece and in particular with cancer care services. As events and feedback on the problems in the Greek healthcare exist, it is expected that they will force policy makers to take action and start considering possible solutions (Kingdon 1997). Depending on the severity of the problems and the time limit for solutions, decision makers may introduce a policy based on either already existing guidelines or order a research to provide evidence based policies. The decision making process in healthcare is complicated and several authors refer to it as the context of policy making (Dobrow *et al.* 2004). The current study could form part of the context of the decision making process, providing invaluable information to decision makers for developing and improving cancer care services. It should be acknowledged that within this context various groups interact such as decision makers, healthcare professionals, political representatives and financial advisers. However, it has been noted that these groups may not address the processes of care and outcomes that are most important to citizens, consumers or patients (Thornton *et al.* 2003).

The concept of user involvement has been introduced to describe the participation of healthcare users in the process of decision making either on treatment options or developing healthcare services. User involvement is generally assumed to be of benefit to both service providers and to those users who participate (Gott *et al.* 2002). However, there is little evidence in the literature about the benefits of including all the different actors in the decision making process of prioritisation of health services in terms of equitable access or health outcomes (Stronks *et al.* 1997).

Robson *et al.* (1997) have revealed that participants in their study saw conflicts emerging from the different interests and experiences among users and professional staff. Healthcare providers and users also expressed opposing views in the current study. The 18 categories that both groups shared were ranked differently by the two

panels. Healthcare providers seemed more knowledgeable of the cancer situation not only in Greece but in the rest of the world. Their suggestions and prioritisations were closer to those suggested in the literature and the guidelines proposed by WHO (2002). That was the issue in Stronks *et al. 's* (1997) study of exploring the choices of patients, the public, healthcare professionals and health insurers regarding priorities in health care where it was revealed that healthcare professionals were more concerned about the common good and the distribution of services.

On the contrary, healthcare users in the current study were more focused on cancer patients' survival, giving priority to cancer patients' treatment and early diagnosis. Stronks *et al.* (1997) have also identified a self interest as a basis for prioritising among patients. In addition, studies that have focused on aspects of care and the way it is perceived have revealed that healthcare users tend to focus on physical care while health professionals focus on psycho-social aspects of care (Larsson *et al.* 1998).

One of the arguments for not involving healthcare users in the decision making process is that they are not well informed about these issues (Poulton 1999). This study revealed that healthcare users' prioritisation on cancer care services was not the same as that provided by healthcare professionals. It could be argued that healthcare users in this study were not knowledgeable about the cancer situation in Greece and that was why their prioritisation differed. However, the users in this study were living through the cancer trajectory and their views were very important. It is reported that users' involvement has contributed to changes to services, however there have been concerns that involving users was used to legitimise decisions that would have been made regardless the users support (Crawford *et al.* 2002). The effects of involvement on accessibility and acceptability of services or impact on the satisfaction, health, or quality of life of health care users has yet to be established (Crawford *et al.* 2002).

6.3 STRENGTHS AND LIMITATIONS OF THE STUDY

After discussing the results, the strengths and weaknesses of the modified Delphi technique that was used to collect and select data and arrive at a consensual priority list in this study will be discussed. One of the main critiques of this methodology concerns the sampling technique, the use of 'experts' and the appropriate number of participants. Keeney *et al.* (2001) suggest that 'Delphi' studies seldom use a randomised sample representative of the target population. By contrast a selection of 'experts' are employed.

The first round Q-Delphi survey with healthcare providers, who provided statements for rating in the next two rounds, consisted of 33.4% doctors, 43.3% nurses and 23.3% support members. According to the number of doctors, nurses and other health professionals working in Greece, the percentage of doctors is 38% and 48% for nurses, while the percentage for the remaining health professionals is 9% (www.statistics.gr).

The percentages of healthcare providers in this study did not reflect the actual percentages of healthcare employees in the Greek NHS as the purpose of sampling for this study was to create a panel of participants who were knowledgeable about cancer issues in Greece and would be able to offer valuable insights based on their experience. As such, it was considered that the 'expert' panel should include key informants, thus taking a purposive sample. For this reason, the reflection of actual percentages of healthcare providers was not a priority in this study. The percentage of the support members was higher than the actual percentage as the researcher did not want the other two groups over-represented in the study. In the sample, the percentage of women was 73.3%. There are no official statistics regarding the gender of healthcare professionals in the Greek NHS. However, recent studies among healthcare professionals, especially nurses, show an over-representation of women in their samples reflecting the high percentage of women in the caring professions (Andrioti *et al.* 1994, Papadimitriou *et al.* 2002). In addition, 25 participants were from Athens and five were form areas outside Athens representing the three large groups in the Q-Delphi with the healthcare providers. Although there appears to be an

imbalance, it has to be considered that almost 50% of the Greek population live in Athens and 58% of the health professionals are concentrated in Athens and Thessaloniki (Sigalas and Petraki 1999).

Healthcare users in this study were from a wide spread geographical area of Greece, despite the fact that they were selected in Athenian hospitals, showing the inter-regional movement of healthcare users. Among the 30 healthcare users of the first round, 27% stated an agricultural or semi-urban district as their permanent residence. Another study in an Athenian university hospital revealed that 38% of the patients were also from areas outside Athens (Merkouris *et al.* 1999). Women *in* the study of healthcare users represented 80% of the participants. A possible explanation is that the carer's role is generally assumed by women in Greece and carers formed half of the sample. In Bellou-Milona *et al.*'s (2001) study, the sample consisted mostly of women (80%) among 149 carers in two general hospitals.

It is acknowledged that the participants in the current study were not randomly selected thus, they should not be considered as representing the whole population of healthcare providers and users. This could have threatened the validity of the results as it would have biased the proposed priorities due to the characteristics of the sample. However, evidence suggests that demographic characteristics do not seem to be systematically related to the decisions people make in prioritising processes (Stronks et al. 1997).

As there exists a debate over the concept of 'experts' in Delphi studies, the panels in both studies were participants who had expertise in the subject area as indicated by Keeney *et al.* (2001). The size of the panel in Delphi studies also varies and there is no consensus on this issue. Bowles (1999), in a review of Delphi studies, reported on panels consisting of a few participants to very large panels of 1,685 individuals. Sumsion (1998) declared that the final number chosen should depend on the topic under investigation and the resources available to the researcher. In this research, the 60 participants who formed the two panels represented a broad spectrum of cancer care provision and the data generated by these two panels was manageable and did not pose any analysis difficulties.

One of the advantages of this methodology is the confidentiality it provides for participants, giving an equal chance for each panel member to present and react to ideas which are unbiased by the identities of other participants (Goodman 1987). In the current study, participants did not know each other which enabled them to be open and truthful about their views. However, participants were known to the researcher which had an effect on the response rate as non respondents could be contacted by the researcher (Keeney *et al.* 2001).

Some authors have also expressed caution about the reliability and validity of Delphi technique. Reliability is the extent to which a procedure produces similar results under constant conditions on all occasions (Hasson *et al.* 2000). Schopper *et al.* (2000) imply that the reliability of the Delphi technique depends on the selection, responsiveness and quality of the participants, the size of the panels and the number of rounds.

The selection of the participants was performed by the researcher using predetermined strict inclusion criteria (chapter 3.4.1 and 3.5.1) which can be easily reproduced to generate the same type of panels. The response rate was also acceptable for this type of survey and exceeded 77% for both studies during all rounds. Sumsion (1998) has suggested that a 70% response rate is required for each round in order to maintain the rigour of this technique. The quality of the participants was also evident based on the wide range of statements they produced and their commitment to the research.

With regards to the validity of Delphi technique, Goodman (1987) states that if the panels participating in the study have the background knowledge and an interest in the topic under investigation, content validity can be assumed. In this study, content validity was assured given that participants were knowledgeable of cancer care in Greece. In addition, content validity was established by the external panel that performed the content analysis of the statements in the first round of the Q-Delphi. Both Q-Delphi studies were face valid in measuring what they claimed to measure (Polit and Beck 2004). Pilot testing the first round of Q-Delphi assured face validity.

6.4 SUMMARY OF DISCUSSION

In this chapter, the findings from the Q-Delphi studies regarding the elements that should be given high priority in the area of cancer care in Greece were discussed based on the WHO strategies and recommendations on the establishment of national cancer control programmes (WHO 2002). For the areas of prevention, early diagnosis, treatment and palliative care that WHO has suggested action to be taken, it was revealed that there were several elements prioritised by the participants in accordance with the WHO guidelines. The WHO (2002) conceptual framework proved valuable in the discussion of the findings in this study.

The role of the current study as part of the context of a policy making process to develop and improve cancer care services was discussed. In addition, the concept of user involvement in the planning and development of cancer services was identified as essential, forming part of the policy making context. The views of healthcare users in this study might have not been in close accordance with the WHO (2002) guidelines, however their views were considered invaluable as they are the ones who live through the cancer trajectory.

The current study was not a satisfaction survey, however the high prioritisation given to more than half of the statements by the participants was regarded as dissatisfaction with the existing situation and that participants would like to see considerable improvements in the area of cancer care. Finally, the strengths and limitations of the study were presented.

The next chapter will provide the conclusion and recommendations for future research and practice.

CHAPTER SEVEN

7. CONCLUSIONS AND RECOMMENDATIONS

Cancer is a disease with a profound effect on every aspect of life. It affects one in three people in Europe and despite improvements in cure rates, many uncertainties persist concerning the nature and causes of cancer and methods of prevention and cure. Cancer creates a burden on every country, not only on the health services but at the level of work-force as it is one of the causes of premature mortality.

Healthcare services have not evolved as it has been expected in Greece, especially after the establishment of the National Health System (NHS) in 1983. As a result, great levels of dissatisfaction exist among healthcare providers and users of the Greek NHS in general and in particular with the services provided. The decision making process regarding the development and improvement of services is held centrally and healthcare users are not involved. As there is no evaluation survey focusing on areas of cancer care provision in Greece, it was the researcher's view that the same level of dissatisfaction would exist. It was also anticipated that healthcare providers who usually take part in the policy making process would have different views from those of the healthcare users. These problems formed the basis of investigation into the areas of cancer care and the type of services that would form a priority for both healthcare providers and healthcare users in Greece. These views were then compared with the recommendations made by the World Health Organisation for the establishment of a national cancer control programme that is relevant to Greece.

The method that was used to identify the issues relevant to the study and to establish the priorities among both groups was a modified Delphi technique. This modified technique was named Q-Delphi and it was the effort of the researcher to introduce a more rigid and objective approach in the Delphi methodology. In Q-Delphi, the analysis of the first round was performed by a panel of experts in healthcare research and the final round which consisted of the consensual items asked the participants to

rank them in order. This method provided the opportunity for participants to express their views and then rate them without having to meet with the rest of the participants. An important feature of any Delphi technique is that of consensus among the participants through the consecutive rounds of questionnaires. This method helped to answer the research question within this study and provided not only the priorities that were needed in the area of cancer care services but the agreement among the participants in these prioritisations.

The highest prioritised categories identified by healthcare providers focused on working conditions and staff shortages. Healthcare providers also highly rated issues such as pain management, the creation of day units and communication. Furthermore, priority was given to home care, prevention, psychological support to patients and the education of health professionals. An important issue such as the creation of a national cancer registration was also regarded as a high priority among healthcare providers. These categories included priority statements that were consensual between the healthcare providers.

The healthcare providers' consensual priorities focused on the shortage of specialised nursing personnel, the operation of oncology hospitals, the development of all types of acceptable special services in these hospitals and the role of the media in cancer prevention. There was also agreement on the creation of accessible specialised services in different parts of Greece so that cancer patients would not have to travel far for treatment. Healthcare providers agreed on the need for better education on every level, especially on communication skills. Consideration was also given and consensus was achieved for the need of psychological support for cancer patients and the need for palliative care either at home or in special institutions.

The statements provided by healthcare users were not identical with those of healthcare providers. However, the categories that were created by the external panel who conducted the content analysis were in close agreement. The prioritised categories for healthcare users were focused on effective treatment and research in discovering more effective treatments. Priority was also given to the organisation of cancer care and the financial support that cancer patients should receive if they have

to pay for special tests and treatment. The education of health professionals was also highly prioritised particularly in the development of healthcare professionals' skills.

It should be noted that the intention was not only to prioritise the categories but also to reach a level of consensus among healthcare users. Agreement was achieved in the area of health professionals' education so that they are better able to understand and diagnose the early signs of cancer. Under the category 'organisation', statements which reached consensus suggested better allocation of special equipment so that cancer patients do not have to be transferred for special examinations and the faster completion of biopsies. Agreement was achieved on issues such as the increment of specialised healthcare personnel and the number of beds for cancer patients. Healthcare users agreed on the priority of psychological support not only for cancer patients but also for their relatives as well as the improvement in the supply of opioid analgesics.

The WHO scenarios for countries in establishing national cancer control programmes proved valuable in creating a conceptual framework for this study. The 'ideal type' medium level scenario considered appropriate for Greece provided the standards from which healthcare providers' and users' views were compared. Most of the suggestions for the medium level scenario were also mentioned by the participants in this study. However, healthcare providers and healthcare users differed in their prioritisation. WHO emphasises on the area of palliative care including pain management and psychological support. Healthcare providers gave higher priority to issues such as palliative care. By contrast, healthcare users focused mainly on the area of treatment. Issues that are considered essential in palliative care were not as highly rated by healthcare users in this study.

Healthcare providers were more knowledgeable of the cancer situation in Greece and their priorities were similar to those suggested in the literature and those provided in the middle level scenario provided by WHO. Healthcare users, under the stress of having cancer, which is still associated with death in Greece, were understandably concerned with the survival of cancer patients and the physical exhaustion of treatments. Given the subjectiveness of their situation, there is the view that

healthcare users should not be involved in policy making meetings. However, cancer patients and their carers are the users of services and should participate in their development and improvement by providing their views as their experiences of service provision are valuable.

From the findings in the current study, several conclusions can be made. The health system in Greece has not evolved as well as it was hoped and this has created problems in the provision of cancer services and cancer care. Healthcare providers and healthcare users know what they want to see improved and developed in these two areas and they have provided their priorities. The evidence produced in this study confirmed the researcher's initial views that there was dissatisfaction in the area of cancer care and that healthcare providers and healthcare users would have different views. The findings have demonstrated that the scenarios provided by WHO for the development of national cancer control programmes are well documented, however it seems that the views of healthcare users have been partly ignored. Policy makers and programmes such as those suggested by WHO should take into account the views of cancer patients and their carers since they are the ones who are going to be directly affected.

7.1 RECOMMENDATIONS AND IMPLICATIONS FOR PRACTICE

Based on the international literature, the WHO medium level scenario for establishing national cancer control programmes, the findings of the current study and the limited resources available for healthcare in Greece, it was anticipated that priority should be given to the following areas:

- The creation of a national cancer registry in order to establish the extent of the problem in Greece and an evaluation of the provision of cancer care and cancer services in the future;

- Increasing nursing personnel so that all posts are covered and services like home care and day units may start operating. The legislation for the creation of home care and day units services exists but it is not realised due to personnel shortages

In line with the first point above, a national cancer registry was attempted in the early 1990s but due to a lack of support and resources it does not exist anymore. According to the International Agency for Research in Cancer (1999), cancer registries are not very expensive to run and sustain. In that case, the establishment of a national cancer registry would not require excessive funding by the Greek state and it would provide valuable information on the exact burden of cancer in Greece.

With regards to the second point, the shortage of nursing personnel is well acknowledged even by the Greek state (www.ypyp.gr). It is anticipated that the employment of a large number of nurses to cover the existing vacancies would have enormous financial implications. However, there should be a plan for a gradual increase in nurse employment. It should be noted that covering the vacancies would assist the entire healthcare system and not just cancer care.

Emphasis should be given to the area of palliative care and its essential components of pain management and psychological support:

- The provision of opioid analgesics should become more widespread.

It is anticipated that with certain amendments in the current legislation the procedure of supplying opioid analgesics may become more effective.

- Psychologists in conjunction with well trained nurses should provide psychological support.

It is acknowledged that further resources are required to provide psychological support to cancer patients and their families. However, the existing personnel could be offered short training courses in order to assess psychological problems and provide effective psychological support.

The issue of communication and information among healthcare professionals and users must be revisited in the Greek culture so that a more open approach is adopted. Cancer patients and their carers should be informed about the cancer patient's diagnosis, taking into account the willingness of a patient to be informed. Greater attention should also be given to the training of health professionals in communication skills. Curricula in the educational institutes that prepare healthcare professionals should provide compulsory communication skills training.

Given the existence of a level of infrastructure in the Greek National Health System, an effort should be made in order that the bio-medical technology is equally distributed throughout Greece. This would help cancer patients to be treated closer to their home and would limit the inter-regional flows of patients. In doing so, the extra costs that some cancer patients are obliged to pay in travelling and private healthcare would be reduced.

Greater emphasis should also be given to the control of tobacco. As tobacco is responsible for various diseases, funding could be provided to establish a national programme for controlling tobacco. An effective tobacco control programme would benefit the whole population by preventing not only cancer but also other tobacco related diseases.

The scenario provided by WHO could be adopted by the Greek state in order to organise a national cancer control programme. However, it should be noted that the views of healthcare users are fundamental to the successful implementation of such a programme.

7.2 RECOMMENDATIONS FOR FUTURE RESEARCH AND RESEARCHERS

One of the natural strengths of any research is that after the main research question is addressed, several other research questions will arise. Depending on the size and scope of these new questions some of these could naturally be accommodated within the body of the current work and some others would be left for further research. That would depend on the nature of their relationship with the current objectives and the time and efforts they require. Among the latter ones relating to this research work are:

- This study did not provide a validation of the actual level of services provided in any of the specific areas of cancer care. This is an area that needs to be investigated.

- It was not expected that the dissatisfaction among healthcare providers and healthcare users would have resulted in the participants in this study rating more than half of the statements in the second round very highly. This posed problems in establishing priorities when most of the statements were regarded as very important. The Likert type scale was useful. However, a different wording would have helped to set priorities more directly. For example, instead of asking to rate the lowest or highest priority, elements could be rated by their level of desirability.

- Future research should target a wider spectrum of healthcare providers and users in order to avoid possible bias. There may be an argument that those who agreed to participate in this study were a minority.

- 'Delphi' technique might not be a suitable methodology for research involving cancer patients. Some rounds may take a long time to be completed and some participants could deteriorate or even die, making it difficult or impossible to participate in the consecutive rounds.

- This study was not a direct satisfaction survey for cancer care services. A satisfaction orientated survey might be needed to establish the levels of satisfaction among healthcare users in the area of cancer care services.

- Although this study did not try to test any hypothesis, it has identified several issues in the area of cancer care services that could form hypotheses to be tested in the future. For example:

    1. Can national cervical screening decrease cervical cancer incidence and mortality in Greece?
    2. Is there a need for hospices in Greece?
    3. Would Greek patients want to be informed if they had cancer?

- A new Delphi technique (Q-Delphi) was introduced as an extension of the classical Delphi technique in this thesis. This modification added an objectivity element in the first round analysis of Delphi technique. In addition, the participants were asked in round three to rank the consensual statements of round two. Q-Delphi technique can be used in the future and other researchers may evaluate its objectivity.

7.3 CONTRIBUTION TO HEALTHCARE KNOWLEDGE

The current study has contributed to knowledge in the area of cancer services development and the area of cancer care in the following ways:

- This research started as an investigation into the areas of cancer care and cancer services needed to be developed in Greece. However, it became clear from the participants' ratings that there was dissatisfaction with cancer care in Greece. This implies the need for more research in the area of cancer care in Greece;

- The 'Delphi' technique is not a very popular research method in Greece. However, in the current research, it provided an excellent way to capture the diverse views of two non-homogeneous groups of participants and, most importantly, helped to achieve a consensus on certain issues;

- The WHO proposal for the creation of national cancer control programmes in every country and the suggestions provided for the medium level scenario were found to be effective comparative measures for the suggestions made by the participants in this study.

- The different views and the different prioritisation by healthcare providers and users have important implications for the future planning and improvement of cancer care services in Greece.

- Healthcare users have not been involved so far in policy decision making processes in Greece. The current study has been able to provide findings based on a sample of cancer patients and carers, highlighting the need for healthcare users to be involved in decision making and the policy making process.

- The satisfactory response rate (over 77%) for both groups during all the consecutive rounds confirmed the interest of healthcare providers and users to provide their views in the sensitive area of cancer care services and helped to retain the rigour of the technique.

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APPENDICES

Appendix 1

Cost-effectiveness studies in palliative care

Author, country	Year	Patient population	Study design	Results
Zimmer *et al.* USA	1985	158 home-bound patients	Randomised control trial I (n=82 cared by a special home care team) C (n=76 not cared by the above team)	Fewer days in out of home services Fewer hospital and nursing home days
Mor *et al.* USA	1988	A total of 1,754 hospice and non hospice patients	Prospective study of patients and carers attending 40 hospice and 14 conventional care services	Lower costs
Ventafridda *et al.* Italy	1989	60 cancer patients with pain	Prospective study of sequential admissions of patients with terminal cancer with pain	Lower costs for the group cared at home
Addington-Hall *et al.* UK	1992	203 cancer patients expected to live less than one year	Randomised control trial I (n=104 received community based services) C (n=99 received routinely available services)	Fewer days were spent in hospital or hospice Lower cost per person
Hughes *et al.* USA	1992	117 terminally ill male patients	Randomised control trial I (n=86 cared by a specialist team) C (n=85 customary care)	Reduction in total hospital stays Lower cost per person
Lo J. Taiwan	2002	26,809 terminally ill patients	Retrospective study, that used population based insurance claim data	Conventional care costs were 48% higher than hospital based hospice care and 496% higher than home hospice care

Appendix 2

Approval letter by the Research Degree Committee of the University of Glamorgan

Mr Nikolaos Efstathiou
7 Stanlex Street
Senghenydd
Caerphilly
CF83 4HS

Date: 16 October 1996

Ref: JAD/JB/PRD8

Dear Mr Efstathiou,

Registration as a Candidate for University of Glamorgan Research Degree

I am writing to inform you that the University's Research Degrees Committee has registered you for the degree of Doctor of Philosophy.

The period of registration will be at least 36 months part-time, subject to the conditions specified in the University's Research Degrees and Diploma Regulations (copy enclosed) . The registration has been approved based on the information as specified in your form RDC1, with effect from 01 September 1996. Any changes to this information must be approved by the Committee.

Finally. I should like to wish you every success in your research project.

Yours sincerely,

Janet Brennan
Secretary, Research Degrees Committee

Enc.

c.c. Director of Studies: Prof Donna Mead, School of Nursing & Midwifery
Second Supervisor(s): Prof Colin Torrance, School of Nursing & Midwifery

A4

Appendix 3

Accompanying letter to first round questionnaire of health care providers' Q-Delphi study

Nikolaos Efstathiou
136 Vryoulon Str
Kessariani
Athens
GR 16121
Tel. 7290355
6925501
E-mail: nefstath@glam.ac.uk

Athens,

Thank you for accepting, after the information you received by phone, to take part in the study of the cancer services and the areas of cancer care that need to be developed or improved in Greece. This study is part of my doctoral thesis at the University of Glamorgan, School of Nursing and Midwifery, Wales, UK.

Your participation is very important and I hope the method that has been chosen to select data will keep you interested until the completion of the study.

In the envelope you will find a flyer regarding the study and the 'Delphi' technique. You will also find a paper with the first question that provides space for your suggestions (maximum 5 suggestions).

I would be grateful if you write your suggestions as soon as possible and post them back to me in the pre-paid envelope that is also provided.

I would like to thank you again for your participation and I am waiting for your replies.

PS. THE RETURN OF THE QUESTIONNAIRE IMPLIES YOUR AGREEMENT TO PARTICIPATE IN THIS STUDY

N. Efstathiou
RGN, MSc

Νικόλαος Ευσταθίου
Βρυούλων 136
Καισαριανή
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16121
Τηλ. 7290355
6925501
nefstath@glam.ac.uk

Αθήνα,

Σας ευχαριστώ για την αποδοχή, μετά από τις πληροφορίες που λάβατε τηλεφωνικώς, να συμμετέχετε στην έρευνα για τις ογκολογικές υπηρεσίες και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να αναπτυχθούν ή να βελτιωθούν στην Ελλάδα. Αυτή η μελέτη είναι μέρος της διδακτορικής διατριβής μου στο University of Glamorgan, School of Nursing and Midwifery, Ουαλία, Μεγάλη Βρετανία.

Η συμμετοχή σας είναι πολύ σημαντική και ελπίζω ότι η μέθοδος που έχει επιλεγεί για να συλλέξει τα δεδομένα, θα σας κρατήσει το ενδιαφέρον μέχρι την ολοκλήρωση της μελέτης.

Στο φάκελο θα βρείτε ένα φυλάδιο σχετικά με τη μελέτη και την τεχνική "Δελφοί". Θα βρείτε επίσης ένα φύλο με την πρώτη ερώτηση που παρέχει το χώρο για τις προτάσεις σας (μέγιστο 5 προτάσεις).

Θα ήμουν ευγνώμων εάν γράφατε τις προτάσεις σας το συντομότερο δυνατόν και τις επιστρέψετε στον προπληρωμένο φάκελο που παρέχεται επίσης.

Θα επιθυμούσα να σας ευχαριστήσω πάλι για τη συμμετοχή σας και περιμένω τις απαντήσεις σας.

Η ΕΠΙΣΤΡΟΦΗ ΤΟΥ ΕΡΩΤΗΜΑΤΟΛΟΓΙΟΥ ΥΠΟΝΟΕΙ ΤΗ ΣΥΜΦΩΝΙΑ ΣΑΣ ΓΙΑ ΤΗ ΣΥΜΜΕΤΟΧΗ ΣΑΣ ΣΕ ΑΥΤΗΝ ΤΗΝ ΕΡΕΥΝΑ

Ν. Ευσταθίου
Νοσηλευτής, MSc

Appendix 4

Leaflet giving information on Delphi technique to participants of the health care providers' Delphi study

References and bibliography

- Crotty M. (1993) The emerging role of the British nurse teacher in Project 2000 programmes: A Delphi survey. *Journal of Advanced Nursing*, 18, 150-157

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- Papastavrou E. (1996) Delphi technique as a method for nursing research: Critical analysis. *Nosileftiki*, 35 (3), 180-186 (in Greek)

If you would like to have more information on the project or on Delphi technique do not hesitate to contact me:

Nikolaos Efstathiou
RGN, MSc

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Athens
16121

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A9

THE SCHOOL OF NURSING & MIDWIFERY

UNIVERSITY OF GLAMORGAN

The Use of 'Delphi' Technique in the Study of Oncology Services in Greece

INFORMATION ABOUT THE PROJECT

AIM OF THE STUDY

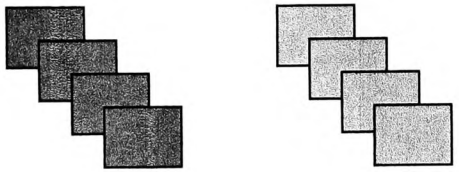
To develop consensus among a group of experts on the cancer services and the areas of cancer care that need to be developed or improved in Greece

HOW 'DELPHI' TECHNIQUE WORKS

- Questionnaires are used for the systematic emergence of a concurrence of judgement or opinion
- The participants are provided with feedback from the whole group's responses
- It provides the participants the opportunity to reformulate their opinions with the knowledge of the group's viewpoint in mind
- Questionnaires are used (usually three rounds) in order to achieve consensus among the participants

WHEN THE USE OF 'DELPHI' TECHNIQUE IS NECESSARY

- In cases where information is needed for issues that we do not know a lot
- In defining concepts and priorities (Mead, 1993)



THE GROUP OF EXPERTS IN THIS STUDY

- Oncology doctors
- Doctors in Health Centres
- Nurses working in Oncology hospitals
- Nurses working in Health Centres
- Home care nurses
- Members of volunteer groups against cancer
- Social workers
- Researchers in oncology

'Delphi' technique seemed appropriate for this study of cancer services and the areas of cancer care that need to be improved in Greece

ADVANTAGES OF 'DELPHI' TECHNIQUE

- It offers anonymity
- It decreases the domination of certain members in the group
- There is no fear of expressing views due to the presence of different professionals in the same group
- The cost and time afforded is less if the members of the group had to meet
- It permits greater geographical representation

Βιβλιογραφία

- Crotty M. (1993) The emerging role of the British nurse teacher in Project 2000 programmes: A Delphi survey. *Journal of Advanced Nursing*, 18, 150-157

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- Mead D. (1993) *The development of primary nursing in National Health Service care giving institutions in Wales*. Unpublished Thesis. University of Wales

- Παπασταύρου Ε. (1996) Η τεχνική 'Δελφοί' στη μεθοδολογία της νοσηλευτικής έρευνας: Κριτική ανάλυση. Νοσηλευτική, 35 (3), 180-186

Εάν θα επιθυμούσατε να έχετε περισσότερες πληροφορίες για την έρευνα ή για την τεχνική 'Δελφοί' μην διστάστε να επικοινωνήσετε μαζί μου:

Νικόλαος Ευσταθίου
Νοσηλευτής, MSc
Βρυούλων 136
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16121

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THE SCHOOL OF NURSING & MIDWIFERY

UNIVERSITY OF GLAMORGAN

Η Τεχνική 'Δελφοί' στην έρευνα για τις ογκολογικές υπηρεσίες στην Ελλάδα

ΠΛΗΡΟΦΟΡΙΕΣ ΓΙΑ ΤΗΝ ΕΡΕΥΝΑ

ΣΚΟΠΟΣ ΤΗΣ ΕΡΕΥΝΑΣ

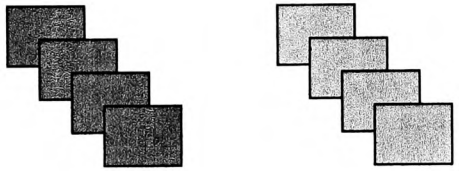
Να αναπτύξει τη συναίνεση μιας ομάδας εμπειρογνωμόνων για τις ογκολογικές υπηρεσίες και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να αναπτυχθούν ή να βελτιωθούν στην Ελλάδα

ΠΩΣ ΛΕΙΤΟΥΡΓΕΙ Η ΤΕΧΝΙΚΗ "ΔΕΛΦΟΙ"

- Χρησιμοποιούνται ερωτηματολόγια προς αναζήτηση της ενημερωμένης κρίσης μιας ομάδας ειδικών
- στους συμμετέχοντες παρέχεται επανατροφοδότηση των απαντήσεων ολόκληρης της ομάδας
- παρέχει στους συμμετέχοντες την ευκαιρία να αλλάξουν γνώμη ή να διαφωνήσουν σε σχέση με τις απόψεις της ομάδας
- χρησιμοποιούνται διαδοχικά ερωτηματολόγια (συνήθως τρεις γύροι) προκειμένου να επιτευχθεί η συναίνεση μεταξύ των συμμετεχόντων

ΠΟΤΕ ΕΙΝΑΙ ΑΠΑΡΑΙΤΗΤΗ Η ΧΡΗΣΗ ΤΗΣ ΤΕΧΝΙΚΗΣ "ΔΕΛΦΟΙ "

- σε περιπτώσεις όπου απαιτείται πληροφόρηση σε ζητήματα για τα οποία δεν γνωρίζουμε πολλά
- Κατά τον ορισμό εννοιών και τον προσδιορισμό προτεραιοτήτων (Mead, 1993)



Η ΟΜΑΔΑ ΕΜΠΕΙΡΟΓΝΩΜΟΝΩΝ ΣΕ ΑΥΤΗΝ ΤΗΝ ΜΕΛΕΤΗ

- ❖ Γιατροί ογκολόγοι
- ❖ Γιατροί στα κέντρα υγείας
- ❖ Νοσηλευτές σε Ογκολογικά Νοσοκομεία
- ❖ Νοσηλευτές σε Κέντρα Υγείας
- ❖ Νοσηλευτές κατ'οίκον νοσηλείας
- ❖ Μέλη εθελοντικών ομάδων κατά του καρκίνου
- ❖ Κοινωνικοί λειτουργοί
- ❖ Ερευνητές σε ογκολογικά θέματα

Η τεχνική "Δελφοί" φαίνεται ότι είναι κατάλληλη για την μελέτη των ογκολογικών υπηρεσιών και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να βελτιωθούν στην Ελλάδα

ΠΛΕΟΝΕΚΤΗΜΑΤΑ ΤΗΣ ΤΕΧΝΙΚΗΣ "ΔΕΛΦΟΙ"

- Προσφέρει ανωνυμία
- Μειώνει την κυριαρχία ορισμένων μελών στην ομάδα
- Δεν υπάρχει κανένας φόβος στην έκφραση των απόψεων λόγω της παρουσίας διαφορετικών επαγγελματιών στην ίδια ομάδα
- Μειώνεται το κόστος και ο χρόνος που θα χρειαζόταν για τη συνάντηση μιας ομάδας
- Επιτρέπει μεγαλύτερη γεωγραφική εκπροσώπηση όσον αφορά τους συμμετέχοντες

Appendix 5

The first round questionnaire

Neoplasms form one of the most common reasons for morbidity and mortality in developed and developing countries. The provision of quality health services to cancer patients is imperative.

In your opinion, which cancer services and which areas of cancer care need to be developed or improved in Greece?

Write your suggestions (maximum 5) in the space provided below:

1. _____

_____

_____

2. _____

_____

_____

3. _____

_____

_____

4. _____

_____

_____

5. _____

_____

_____

Τα νεοπλάσματα αποτελούν μια από τις συχνότερες αιτίες νοσηρότητας και θνησιμότητας τόσο στις αναπτυγμένες χώρες όσο και στις αναπτυσσόμενες. Το ζητούμενο παντού είναι η παροχή ποιοτικών υπερησιών υγείας στους καρκινοπαθείς.

Κατά την άποψή σας, ποιες ογκολογικές υπηρεσίες και ποιοί τομείς στην ογκολογική φροντίδα χρειάζεται να αναπτυχθούν ή να βελτιωθούν στην Ελλάδα;

Γράψτε τις απόψεις σας (το πολύ 5) στο χώρο που προσφέρεται παρακάτω:

1. _____

_____

_____

2. _____

_____

_____

3. _____

_____

_____

4. _____

_____

_____

5. _____

_____

_____

Appendix 6

The second round questionnaire for health care providers

Nikolaos Efstathiou
136 Vryoulon str.
Kessariani
Athens
GR 16121

University of Glamorgan
School of Nursing & Midwifery
Pontypridd
CF37 1DL
Wales, UK

2nd ROUND

The 'Delphi' Technique in the Study of Oncology Services in Greece

How to complete the questionnaire:

Tick the box that describes best your opinion on the priority you would give to the suggestions that follow.

The scale ranges from 'very low priority' (no 1);
'low priority' (no 2);
'medium low priority' (no 3);
'neither low nor high priority' (no 4);
'medium high priority' (no 5);
'high priority' (no 6) and
'very high priority' (no7).

Panel no

1 = Very low priority
7 = Very high priority

Public health / Health promotion

		1	2	3	4	5	6	7
1	6.2 Seminars on cancer prevention should be organised at schools, municipalities, etc.							
2	8.5 Media should provide information to people on cancer prevention							
3	9.4 Cancer prevention programmes should be developed with the co-operation of all health professionals							
4	20.4 Prevention and timely cancer diagnosis. Pre-symptom checking regularly, through proper education and information has as result the decrease of cancer morbidity							
5	21.3 Prevention programmes must be improved							
6	22.2 Health Centres' staff should promote and teach a healthy life style as well the avoidance of smoking and other preventive measures against cancer							
7	24.3 Programmes should be organised by Health Centres and other Primary Health Services on the net (National Network)							
8	25.1 Prevention programmes against cancer should be developed							
9	25.2 Health Centres should focus on prevention as PHS							
10	25.3 Campaigns against smoking should be initiated especially at schools							
11	26.2 Emphasis should be given to prevention by the Health Centres' personnel							

Prevention / Screening

12	24.2 Well organised screening programmes should exist for the population, like PAP test or mammography, and not occasionally as it is nowadays							
13	21.4 Mobile screening groups should perform tests in rural areas							
14	30.5 Screening services in hospitals should be operating for more hours, so that waiting lists get shorter (waiting period for a mammography may take 4 months)							

1 = Very low priority
7 = Very high priority

Special cancer units

		1	2	3	4	5	6	7
15	8.7 Oncology units should be developed in General hospitals							
16	14.1 Oncology patients must be treated in special wards in General hospitals							
17	18.1 Development of tertiary oncology care in large district hospitals							
18	30.3 Cancer hospitals should be built in the greater area of Greece so that cancer patients won't have to travel far for special treatment							
19	14.2 In General hospitals there should be a room for the preparation of chemotherapy as the number of oncology patients in General hospitals is increasing							
20	30.2 Cancer patients wherever they are nursed, they should receive the best treatment possible							
21	4.3 Cancer needs multidisciplinary treatment by specially educated professionals in Oncology hospitals and not out of chance in General hospitals							

Home care

22	1.1 Home care should be developed for cancer patients. This service is limited in the capital of Greece and non-existent in rural areas							
23	4.2 Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life							
24	4.4 Services like home care should be provided by doctors, nurses and social workers							
25	6.3 Home care should be developed for oncology patients not only during treatment but for terminally ill patients							
26	7.5 Home nursing services should be developed							
27	9.1 New cancer services must be developed (day-units, home care services, hospices for terminally ill patients) in the country							
28	10.5 Home care services by all the oncology hospitals							
29	11.1 Home care services. These services should be provided by all oncology hospitals at least							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
30	13.1 Home care services should be developed							
31	14.4 Home care nursing services must be created in all the Oncology hospitals and in some General hospitals too							
32	15.4 Health Centres must be well organised in order to provide home care services							
33	16.1 Home care nursing should be provided by al the Oncology hospitals in Greece							
34	17.1 Well organised oncology care in the patient's house							
35	20.1 Development of cancer patient's care in the community and at home							
36	20.2 There should be a possibility to offer therapeutic programmes and hospice care at home							
37	22.1 Health Centres should provide home care services							
38	25.4 Home care services should be developed by Health Centres							
39	23.1 Health Centres should employ nurses so that home care services may be provided to the community around the Health Centres							

Day units

40	3.2 Day units should be developed as well as special intensive care units, physiotherapy units and home care services in all oncology hospitals							
41	4.6 Day units should be increased in Oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients stay more at their home environment							
42	11.5 Day clinics must be developed							
43	13.2 Day clinics should be developed so that patients may be offered treatment without being admitted in a ward, when it is not possible for the treatment to be done at home							
44	17.3 Oncology care provision in Day units							

1 = Very low priority
7 = Very high priority

Hospices

		1	2	3	4	5	6	7
45	1.2 Hospices should be developed for cancer patients at a terminal stage when it is very difficult or impossible to be treated at home. Their treatment at hospital is costly							
46	6.1 Nursing care for terminally ill patients should be provided in special nursing homes so that patients get special care							
47	11.2 Hospices for cancer patients at the final stage. If possibly this service should be provided in a different place of that of a hospital							
48	15.1 Hospices must be created for the care of terminally ill cancer patients							
49	18.2 Development of palliative care for the patients either at home or in special hospitals and institutions							

Pain management

50	1.3 Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics							
51	2.1 Pain clinics should be created for cancer patients who are at a terminal stage							
52	7.4 Pain management services should be developed in all the hospitals							
53	8.1 Pain management services should be developed by pain clinics, offering pain management not only during treatment but when at home, through all the stages of the disease							
54	11.3 Pain management clinics							
55	13.3 Pain clinics should be developed so that better quality of life is offered to cancer patients							

Hospital environment

56	3.1 Oncology hospitals must become independent, functional, efficient, non-bureaucratic, non-institution look like environment. The environment of oncology hospitals must not bring in mind an impersonal institution							
57	19.5 The buildings where cancer care is provided must be improved							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
58	30.4 The wards where patients are nursed should be improved (some buildings are very old, the rooms are dirty, etc.)							

Health centres

59	17.2 Well organised oncology care in Health Centres							
60	26.1 Health Centres should be developed in such a way so they may offer follow up, cancer care and rehabilitation to patients during recovery							
61	22.3 Health Centres all over Greece must be reinforced so that cancer diagnosis may be done there even in pre-symptomatic stage							

Psychological support

62	2.2 Psychological support should be given by professionals not only on diagnosis but during treatment too							
63	3.4 Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist and social workers							
64	8.3 Psychological support should be provided to cancer patients and their families through all the stages of the disease							
65	10.1 Psychological support services should be developed at the hospitals for cancer patients and their relatives							
66	10.2 Psychological support programmes must be developed in all the country							
67	11.4 Communication and psychological support by all the health professional team (doctor-nurse-social worker-psychiatrist-psychologist-occupational therapist)							
68	12.1 Psychological support for all cancer patients by psychiatrists, psychologists and social workers							
69	14.3 Psychological support groups must be created for the support of patients and families not only in the hospital but in the community too							
70	28.3 Psychological support services must be developed in Oncology hospitals by doctors-social workers-nurses							

1 = Very low priority
7 = Very high priority

			1	2	3	4	5	6	7
71	20.5	Psychological support for nurses working in Oncology wards. Support groups must be created by nurses for nurses in conjunction with counsellors							

Support

72	1.4	Support groups should be created with the participation of professionals working in the cancer services and patients, especially those who have been successfully treated							
73	4.5	Volunteer support groups for cancer patients should be reinforced in oncology hospitals to ascertain the quality of the services provided							
74	27.3	The number of social workers in hospitals should be increased so that cancer patients and their relatives may get better support							

Information

75	28.2	Volunteer and non-volunteer groups should be formed for giving information to cancer patients by the phone							
76	29.1	Services should be developed where cancer patients may receive information regarding their disease							
77	20.3	Cancer patients' education. Information about the disease, the treatment, the recovery and psychological support not only for the patients but their families too							
78	29.3	A national database should be developed regarding the treatment of different cancers so that all patients may receive the best treatment possible							

Communication

79	15.5	All health professionals who come in contact with cancer patients should get special training in communication skills (how to tell the diagnosis, bad news regarding treatment, etc.)							
80	21.1	Communication between health professionals must be improved, so that they may know as much as possible regarding the cancer patient under their care							
81	26.3	The system connecting the Health Centres with the hospitals should be improved							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
82	30.1 The announcement of cancer diagnosis to the patient should be done in the proper place and time							

Financial resources

83	8.2 Financial support for the cancer patient and his/her family, not only during treatment but in cases when the patient can not work							
84	28.4 Financial support should be provided to cancer patients who really need it							
85	8.4 Cancer patients must be covered by their health insurance to have free clinical tests and treatment							
86	27.2 Insurance companies should cover cancer patients during all the phases of the disease (diagnosis-treatment-rehabilitation)							
87	1.5 Wiser financial arrangements should be made so money won't be wasted. Money should be spent wisely for equipment and machinery that is necessary for the treatment of cancer patients							
88	19.1 Financial allowances by the state with committee supervision							

Education / Training

89	4.7 Emphasis should be given in staff's education who work in special oncology hospitals							
90	6.5 Doctors and nurses in oncology hospitals should be specialised in offering personalised care to cancer patients e.g. Pain assessment, vomiting, quality of life							
91	7.1 Educational centres must be developed to provide an oncology nursing specialty							
92	9.2 Education (basic-post-continuing) must be improved for all health professionals (doctors-nurses-psychologists-social workers)							
93	9.3 Oncology nursing specialty should become a reality							
94	10.3 Doctors and nurses must get communication improvement courses							
95	14.5 Doctors and nurses should be properly educated to recognise cancer symptoms at an early stage and diagnosis should be made as soon as possible							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
96	19.4 Nurses' and doctors' education on oncology should be improved, especially regarding the psychological support of cancer patients							
97	20.6 There should be opportunities for basic and post-basic education for all health professionals in oncology wards. Education programmes should be organised as well, and nurses should have the opportunity to take part in order to improve the provision of nursing care							
98	23.3 Education regarding pain management must be improved, so that pain may be treated even in Primary Health Centres (Health Centres, Out-patient clinics, etc.)							
99	28.1 All health professionals should attend seminars on communication skills							
100	10.4 Prevention and management of lemphydema by specialists							

Staff shortages

101	3.5 The big shortage of specialised nursing staff requires the immediate elaboration and application of a total plan for the engagement and staying of nurses in the profession							
102	14.6 Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services							
103	18.4 The number of nursing staff should be increased in Oncology hospitals							
104	18.3 Oncology wards should be staffed with social worker and psychologist							
105	23.2 Chemotherapy could be provided in Health Centres, if there was adequate staff and education was provided							

Hostels

106	12.2 Hostels should be operate close to the Oncology hospitals for patients who come from far away and their relatives							
107	27.4 Hostels should be created for cancer patients and their relatives who come from far away for treatment close to Oncology hospitals							

1 = Very low priority
7 = Very high priority

1 2 3 4 5 6 7

Cancer registration

108 24.1 Registration of all cancers

109 29.2 A registration programmes of all the cancers on national level must be developed

Research

110 5.1 Basic research in cancer must be developed

111 5.2 Applied research must be developed and molecular oncology tests should be done in order to improve the way cancer patients are treated

112 6.4 Clinical oncology nursing research should be developed in order to improve the care provided

113 7.2 Research centres must be developed regarding the care provided to cancer patients

114 19.2 Research groups must be formed, directed by a central committee

Stigma

115 27.1 The "stigma" of cancer must be fought

Organisation

116 15.2 All hospitals should be organised in a way that most of cancer patients may be treated close to their homes

117 24.5 Rehabilitation and palliative care programmes must be organised in urban and rural areas of Greece by special educated people

118 7.3 Committees should be developed for controlling and assessing the care provided to cancer patients

Technology

119 21.2 District General hospitals must be equipped adequately so that cancer diagnosis and treatment may be done there, so there is no need for patients to visit the large Anticancer hospitals

120 24.4 Cancer patients could have their follow up at Health Centres after their treatment at a hospital with the oncologist guiding through on-line computer connection

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
121	4.1 The four Oncology hospitals in Greece must be reinforced with technology and adequate staff							

Waiting lists

122	5.4 Waiting lists should be minimised for admission in Oncology hospitals							

Working conditions

123	3.6 Working conditions must be improved so that working in a hospital becomes less stressful							

Special services

124	19.3 Great attention should be given in bone marrow transplantation							

Networking

125	3.3 Special places should be created in oncology hospitals for nurses, like offices and meeting places, for exchanging ideas and discussing problems of the oncology units							

Occupational therapy

126	8.8 Cancer patients should be kept occupied at the hospital (occupational therapy)							

Education

127	8.6 There should be a possibility for young cancer patients to continue their education at the hospital							

Miscellaneous

128	5.3 Oncology committees must operate in Oncology hospitals not just in "papers"							
129	5.5 Patients' duration of staying at Oncology hospitals should be minimised							
130	15.3 Oncology doctors should have access to databases regarding treatment protocols so that cancer patients may receive the best possible treatment							

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2ος ΓΥΡΟΣ

Η Τεχνική 'Δελφοί' στην Έρευνα για τις Ογκολογικές Υπηρεσίες στην Ελλάδα

Πώς να συμπληρώσετε το ερωτηματολόγιο:

Τοποθετείστε το σημείο X στο τετράγωνο που περιγράφει καλύτερα την γνώμη σας σχετικά με προτεραιότητα που θα δίνατε στις προτάσεις που ακολουθούν.

Η κλίμακα κυμαίνεται από "πολύ χαμηλή προτεραιότητα" (1)
"χαμηλή προτεραιότητα" (2)
"μέση χαμηλή προτεραιότητα" (3)
"ούτε χαμηλή ούτε υψηλή προτεραιότητα" (4)
"μέση υψηλή προτεραιότητα" (5)
"υψηλή προτεραιότητα" (6) και
"πολύ υψηλή προτεραιότητα" (7).

Panel no

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Δημόσια Υγεία/Προαγωγή Υγείας

		1	2	3	4	5	6	7
1	6.2 Πρέπει να οργανωθούν σεμινάρια για την πρόληψη του καρκίνου στα σχολεία, τους δήμους, κ.λ.π.							
2	8.5 Τα media πρέπει να παρέχουν πληροφορίες στον κόσμο για την πρόληψη του καρκίνου							
3	9.4 Πρέπει να αναπτυχθούν προγράμματα πρόληψης του καρκίνου με τη συνεργασία όλων των επαγγελματιών υγείας							
4	20.4 Πρόληψη και έγκαιρη διάγνωση του καρκίνου. Ο τακτικός έλεγχος των προ-συμπτωμάτων, μέσω της κατάλληλης εκπαίδευσης και των πληροφοριών έχει ως αποτέλεσμα τη μείωση της νοσηρότητας από καρκίνο							
5	21.3 Τα προγράμματα πρόληψης πρέπει να βελτιωθούν							
6	22.2 Το προσωπικό στα Κέντρα Υγείας πρέπει να προωθεί και να διδάσκει υγιή τρόπο διαβίωσης, επίσης την αποφυγή του καπνίσματος και άλλα προληπτικά μέτρα κατά του καρκίνου							
7	24.3 Πρέπει να οργανωθούν προγράμματα από τα Κέντρα Υγείας και άλλες πρωτοβάθμιες υγειονομικές υπηρεσίες σε δίκτυο (Εθνικό Δίκτυο)							
8	25.1 Πρέπει να αναπτυχθούν προγράμματα πρόληψης κατά του καρκίνου							
9	25.2 Τα κέντρα υγείας πρέπει να εστιάσουν στην πρόληψη ως ΠΥΥ							
10	25.3 Πρέπει να αρχίσουν εκστρατείες ενάντια στο κάπνισμα, ειδικά στα σχολεία							
11	26.2 Έμφαση πρέπει να δοθεί στην πρόληψη από το προσωπικό στα Κέντρα Υγείας							

Πρόληψη/ Screening

12	24.2 Καλά οργανωμένα προγράμματα πρόληψης (screening) πρέπει να υπάρχουν για όλο τον πληθυσμό, όπως τεστ pap ή μαστογραφίες, και όχι περιστασιακά όπως είναι σήμερα							
13	21.4 Κινητές μονάδες προληπτικού ελέγχου πρέπει να διενεργούν ελέγχους στις αγροτικές περιοχές							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
14	30.5 Οι υπηρεσίες προληπτικού ελέγχου στα νοσοκομεία πρέπει να λειτουργούν περισσότερες ώρες, έτσι ώστε οι λίστες αναμονής να είναι μικρότερες (η περίοδος αναμονής για μια μαστογραφία μπορεί να πάρει 4 μήνες)							

Ειδικές Ογκολογικές Μονάδες

15	8.7 Ογκολογικές μονάδες πρέπει να αναπτυχθούν στα γενικά νοσοκομεία							
16	14.1 Οι ασθενείς με καρκίνο πρέπει να νοσηλεύονται σε ειδικούς θαλάμους στα γενικά νοσοκομεία							
17	18.1 Ανάπτυξη τριτοβάθμιας ογκολογικής φροντίδας στα μεγάλα νοσοκομεία της περιφέρειας							
18	30.3 Ογκολογικά νοσοκομεία πρέπει να χτιστούν στη ευρύτερη περιοχή της Ελλάδας έτσι ώστε οι ασθενείς με καρκίνο να μην χρειάζεται να ταξιδεύουν μακριά για ειδικές θεραπείες							
19	14.2 Στα γενικά νοσοκομεία πρέπει να υπάρχει ειδικός χώρος για την προετοιμασία της χημειοθεραπείας δεδομένου ότι ο αριθμός ογκολογικών ασθενών στα γενικά νοσοκομεία αυξάνεται							
20	30.2 Οι ασθενείς με καρκίνο οπουδήποτε νοσηλεύονται, πρέπει να λαμβάνουν την καλύτερη δυνατή θεραπεία							
21	4.3 Η θεραπεία του καρκίνου απαιτεί διεπιστημονική προσέγγιση από ειδικά εκπαιδευμένους επαγγελματίες σε ογκολογικά νοσοκομεία και όχι τυχαία στα γενικά νοσοκομεία							

Κατ' οίκον Νοσηλεία

22	1.1 Η κατ' οίκον νοσηλεία πρέπει να αναπτυχθεί για τους ασθενείς με καρκίνο. Αυτή η υπηρεσία είναι περιορισμένη στην πρωτεύουσα της Ελλάδας και ανύπαρκτη στις αγροτικές περιοχές							
23	4.2 Υπηρεσίες σαν την κατ' οίκον νοσηλεία πρέπει να αναπτυχθούν για τους αρρώστους τελικού σταδίου με καρκίνο, για καλύτερη ποιότητα ζωής στα τελευταία στάδια της ζωής							
24	4.4 Υπηρεσίες όπως η κατ' οίκον νοσηλεία πρέπει να προσφέρονται από τους γιατρούς, τις νοσηλεύτριες και τους κοινωνικούς λειτουργούς							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
25	6.3 Η κατ' οίκον νοσηλεία πρέπει να αναπτυχθεί για τους ασθενείς με καρκίνο όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και για τους ασθενείς τελικού σταδίου							
26	7.5 Πρέπει να αναπτυχθούν οι κατ' οίκον νοσηλευτικές υπηρεσίες							
27	9.1 Νέες ογκολογικές υπηρεσίες πρέπει να αναπτυχθούν (μονάδες ημερήσιας νοσηλείας-μονάδες οικιακής φροντίδας, ιδρύματα για τους ασθενείς τελικού σταδίου) σε όλη τη χώρα							
28	10.5 Υπηρεσίες οικιακής φροντίδας από όλα τα νοσοκομεία ογκολογίας							
29	11.1 Υπηρεσίες οικιακής φροντίδας. Αυτές οι υπηρεσίες πρέπει να παρέχονται από όλα τα ογκολογικά νοσοκομεία τουλάχιστον							
30	13.1 Πρέπει να αναπτυχθούν υπηρεσίες κατ' οίκον νοσηλείας							
31	14.4 Υπηρεσίες νοσηλείας κατ' οίκον πρέπει να δημιουργηθούν σε όλα τα νοσοκομεία ογκολογίας και σε μερικά γενικά νοσοκομεία επίσης							
32	15.4 Τα Κέντρα Υγείας πρέπει να οργανωθούν καλά προκειμένου να παρέχουν υπηρεσίες οικιακής φροντίδας							
33	16.1 Η κατ' οίκον νοσηλεία πρέπει να παρέχεται από όλα τα ογκολογικά νοσοκομεία στην Ελλάδα							
34	17.1 Καλά οργανωμένη ογκολογική φροντίδα στο σπίτι του ασθενή							
35	20.1 Ανάπτυξη της νοσηλείας του ασθενή με καρκίνο στην κοινότητα και στο σπίτι							
36	20.2 Πρέπει να υπάρχει η δυνατότητα να προσφέρονται θεραπευτικά προγράμματα και φροντίδα τελικού σταδίου στο σπίτι							
37	22.1 Τα Κέντρα Υγείας πρέπει να παρέχουν υπηρεσίες κατ' οίκον φροντίδας							
38	25.4 Υπηρεσίες κατ' οίκον νοσηλείας πρέπει να αναπτυχθούν από τα Κέντρα Υγείας							
39	23.1 Τα Κέντρα Υγείας πρέπει να προσλάβουν νοσηλεύτριες ώστε οι υπηρεσίες κατ' οίκον νοσηλείας να μπορούν να παρασχεθούν στην κοινότητα γύρω από τα Κέντρα Υγείας							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Μονάδες Ημέρας

		1	2	3	4	5	6	7
40	3.2 Μονάδες ημερήσιας νοσηλείας πρέπει να αναπτυχθούν καθώς επίσης και ειδικές μονάδες εντατικής παρακολούθησης, μονάδες φυσιοθεραπείας και υπηρεσίες κατ' οίκον νοσηλείας σε όλα τα ογκολογικά νοσοκομεία							
41	4.6 Οι μονάδες ημερήσιας νοσηλείας πρέπει να αυξηθούν στα ογκολογικά νοσοκομεία προκειμένου να εξυπηρετηθούν περισσότεροι ασθενείς με καρκίνο (μονάδες ημέρας για ακτινοθεραπεία των εξωτερικών ασθενών), ώστε οι ασθενείς να μένουν περισσότερο στο οικογενειακό περιβάλλον τους							
42	11.5 Πρέπει να δημιουργηθούν κλινικές ημέρας							
43	13.2 Πρέπει να αναπτυχθούν κλινικές ημερήσιας νοσηλείας ώστε οι ασθενείς να λαμβάνουν θεραπεία χωρίς να χρειάζεται να κάνουν εισαγωγή στο νοσοκομείο, όταν δεν είναι δυνατό η θεραπεία να γίνει στο σπίτι							
44	17.3 Παροχή ογκολογικής φροντίδας στις μονάδες ημέρας							

Ξενώνες για αρρώστους τελικού σταδίου

		1	2	3	4	5	6	7
45	1.2 Πρέπει να δημιουργηθούν ιδρύματα για τους ασθενείς με καρκίνο σε τελικό στάδιο όταν είναι πολύ δύσκολο ή αδύνατο να νοσηλεύονται στο σπίτι. Η νοσηλεία τους στο νοσοκομείο είναι δαπανηρή							
46	6.1 Η νοσηλεία των ασθενών τελικού σταδίου πρέπει να παρέχεται σε ειδικούς χώρους ώστε οι ασθενείς να έχουν ειδική φροντίδα							
47	11.2 Ειδικά ιδρύματα για τους ασθενείς με καρκίνο τελικού σταδίου. Εάν είναι δυνατόν αυτή η υπηρεσία θα πρέπει να παρέχεται σε διαφορετικό χώρο από αυτό του νοσοκομείου							
48	15.1 Ειδικά ιδρύματα πρέπει να δημιουργηθούν για την φροντίδα των ογκολογικών ασθενών τελικού σταδίου							
49	18.2 Ανάπτυξη της παρηγορητικής φροντίδας για τους ασθενείς είτε στο σπίτι είτε στα ειδικά νοσοκομεία και τα ιδρύματα							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Αντιμετώπιση του Πόνου

		1	2	3	4	5	6	7
50	1.3 Μεγάλη προσοχή πρέπει να δοθεί στην αντιμετώπιση του πόνου. Οι επαγγελματίες υγείας πρέπει να ενημερώνονται και να εκπαιδεύονται στην αντιμετώπιση του πόνου. Κλινικές πόνου							
51	2.1 Κλινικές πόνου πρέπει να δημιουργηθούν για τους ασθενείς με καρκίνο που είναι στο τελικό στάδιο							
52	7.4 Πρέπει να αναπτυχθούν σε όλα τα νοσοκομεία υπηρεσίες αντιμετώπισης του πόνου							
53	8.1 Αντιμετώπιση του πόνου από τις κλινικές πόνου, προσφέροντας αντιμετώπιση του πόνου όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και στο σπίτι, σε όλα τα στάδια της ασθένειας							
54	11.3 Κλινικές αντιμετώπισης πόνου							
55	13.3 Κλινικές πόνου πρέπει να αναπτυχθούν ώστε να προσφέρεται καλύτερη ποιότητα ζωής στους ασθενείς με καρκίνο							

Περιβάλλον Νοσοκομείων

56	3.1 Τα ογκολογικά νοσοκομεία πρέπει να είναι ανεξάρτητα, λειτουργικά, αποδοτικά, μη-γραφειοκρατικά, χωρίς το περιβάλλον να θυμίζει ίδρυμα. Το περιβάλλον των ογκολογικών νοσοκομείων δεν πρέπει να φέρνει στο μυαλό ένα απρόσωπο ίδρυμα							
57	19.5 Τα κτήρια όπου παρέχεται ογκολογική φροντίδα πρέπει να βελτιωθούν							
58	30.4 Οι θάλαμοι όπου οι ασθενείς νοσηλεύονται πρέπει να βελτιωθούν (μερικά κτήρια είναι πολύ παλαιά, τα δωμάτια είναι βρώμικα, κ.λ.π.)							

Κέντρα Υγείας

59	17.2 Καλά οργανωμένη παροχή ογκολογικής φροντίδας στα Κέντρα Υγείας							
60	26.1 Τα Κέντρα Υγείας πρέπει να αναπτυχθούν με τέτοιο τρόπο έτσι ώστε να προσφέρουν επανέλεγχο, ογκολογική φροντίδα και αποκατάσταση στους ασθενείς							
61	22.3 Τα Κέντρα Υγείας σε όλη την Ελλάδα πρέπει να ενισχυθούν ώστε η διάγνωση του καρκίνου να μπορεί να γίνει εκεί, ακόμη και στο προσυμπτωματικό στάδιο							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Ψυχολογική υποστήριξη

		1	2	3	4	5	6	7
62	2.2 Ψυχολογική υποστήριξη πρέπει να παρέχεται από τους επαγγελματίες όχι μόνο κατά τη διάγνωση αλλά και κατά τη διάρκεια της θεραπείας							
63	3.4 Ομάδες ψυχολογικής υποστήριξης πρέπει να δημιουργηθούν στα ογκολογικά νοσοκομεία, και να αποτελούνται από ψυχίατρο, νοσηλεύτριες, ψυχολόγο και κοινωνικούς λειτουργούς							
64	8.3 Ψυχολογική υποστήριξη πρέπει να παρέχεται στους ασθενείς με καρκίνο και τις οικογένειές τους σε όλα τα στάδια της ασθένειας							
65	10.1 Υπηρεσίες ψυχολογικές υποστήριξης πρέπει να αναπτυχθούν στα νοσοκομεία για τους ασθενείς με καρκίνο και τους συγγενείς τους							
66	10.2 Προγράμματα ψυχολογικής υποστήριξης πρέπει να αναπτυχθούν σε όλη τη χώρα							
67	11.4 Επικοινωνία και ψυχολογική υποστήριξη από όλη την ομάδα επαγγελματιών υγείας (γιατρός-νοσηλευτής-κοινωνικός λειτουργός-ψυχίατρος-ψυχολόγος-εργοθεραπευτής)							
68	12.1 Ψυχολογική υποστήριξη για όλους τους ασθενείς με καρκίνο από ψυχιάτρους, ψυχολόγους και κοινωνικούς λειτουργούς							
69	14.3 Ομάδες ψυχολογικές υποστήριξης πρέπει να δημιουργηθούν για την υποστήριξη των ασθενών και των οικογενειών τους όχι μόνο στο νοσοκομείο αλλά και στην κοινότητα							
70	28.3 Υπηρεσίες ψυχολογικής υποστήριξης πρέπει να αναπτυχθούν στα ογκολογικά νοσοκομεία από γιατρούς-κοινωνικούς λειτουργούς-νοσηλευτές							
71	20.5 Ψυχολογική υποστήριξη για τους νοσηλευτές που εργάζονται σε ογκολογικές μονάδες. Οι ομάδες υποστήριξης πρέπει να δημιουργηθούν από τους νοσηλευτές για τους νοσηλευτές σε συνεργασία με ειδικούς συμβούλους							

Υποστήριξη

72	1.4 Ομάδες υποστήριξης πρέπει να δημιουργηθούν, με συμμετοχή των επαγγελματιών που εργάζονται στις ογκολογικές υπηρεσίες και των ασθενών, ειδικά εκείνων που έχουν θεραπευθεί επιτυχώς							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
73	4.5 Οι εθελοντικές ομάδες υποστήριξης για τους ασθενείς με καρκίνο πρέπει να ενισχυθούν στα ογκολογικά νοσοκομεία για να βεβαιώνουν την ποιότητα των παρεχόμενων υπηρεσιών							
74	27.3 Ο αριθμός των κοινωνικών λειτουργών στα νοσοκομεία πρέπει να αυξηθεί ώστε οι ασθενείς με καρκίνο και οι συγγενείς τους να έχουν καλύτερη υποστήριξη							

Πληροφόρηση

75	28.2 Εθελοντικές και μη-εθελοντικές ομάδες πρέπει να δημιουργηθούν για να δίνουν πληροφορίες στους ασθενείς με καρκίνο μέσω τηλεφώνου							
76	29.1 Πρέπει να αναπτυχθούν υπηρεσίες όπου οι ασθενείς με καρκίνο να μπορούν να λάβουν πληροφορίες σχετικά με την ασθένειά τους							
77	20.3 Εκπαίδευση των ασθενών με καρκίνο. Πληροφορίες για την ασθένεια, τη θεραπεία, την αποκατάσταση και ψυχολογική υποστήριξη όχι μόνο για τους ασθενείς αλλά και τις οικογένειές τους							
78	29.3 Πρέπει να αναπτυχθεί Εθνική βάση δεδομένων σχετικά με τη θεραπεία των διαφορετικών μορφών του καρκίνου ώστε όλοι οι ασθενείς να μπορούν να λάβουν την καλύτερη πιθανή θεραπεία							

Επικοινωνία

79	15.5 Όλοι οι επαγγελματίες υγείας που έρχονται σε επαφή με τους ασθενείς με καρκίνο πρέπει να λαμβάνουν ειδική κατάρτιση όσον αφορά την επικοινωνία (πώς να ανακοινώνεται η διάγνωση, δυσάρεστες ειδήσεις σχετικά με τη θεραπεία, κ.λ.π.)							
80	21.1 Η επικοινωνία μεταξύ των επαγγελματιών υγείας πρέπει να βελτιωθεί, ώστε να ξέρουν όσο το δυνατόν περισσότερα σχετικά με τον ασθενή με καρκίνο υπο τη φροντίδα τους							
81	26.3 Το σύστημα που συνδέει τα Κέντρα Υγείας με τα νοσοκομεία πρέπει να βελτιωθεί							
82	30.1 Η ανακοίνωση της διάγνωσης του καρκίνου στον ασθενή πρέπει να γίνεται στον κατάλληλο τόπο και χρόνο							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
Οικονομικοί πόροι								
83	8.2 Οικονομική ενίσχυση για τους ασθενείς με καρκίνο και την οικογένειά τους, όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και σε περιπτώσεις που δεν μπορεί να εργαστεί ο ασθενής	☐	☐	☐	☐	☐	☐	☐
84	28.4 Οικονομική ενίσχυση πρέπει να παρέχεται στους ασθενείς με καρκίνο που την χρειάζονται πραγματικά	☐	☐	☐	☐	☐	☐	☐
85	8.4 Οι ασθενείς με καρκίνο πρέπει να καλύπτονται από την ασφάλεια υγείας τους και να μην πληρώνουν για τις εξετάσεις και την θεραπεία	☐	☐	☐	☐	☐	☐	☐
86	27.2 Οι ασφαλιστικές εταιρείες πρέπει να καλύπτουν τους ασθενείς με καρκίνο κατά τη διάρκεια όλων των φάσεων της ασθένειας (διάγνωση-θεραπεία-αποκατάσταση)	☐	☐	☐	☐	☐	☐	☐
87	1.5 Προσεκτικές οικονομικές ρυθμίσεις πρέπει να γίνουν ώστε να μην σπαταλούνται χρήματα. Τα χρήματα πρέπει να ξοδεύονται σοφά για εξοπλισμό και μηχανήματα που είναι απαραίτητα για τη θεραπεία των ασθενών με καρκίνο	☐	☐	☐	☐	☐	☐	☐
88	19.1 Οικονομικά επιδόματα από το κράτος για τους καρκινοπαθείς υπο την επίβλεψη επιτροπών	☐	☐	☐	☐	☐	☐	☐
Εκπαίδευση/Κατάρτιση								
89	4.7 Έμφαση πρέπει να δοθεί στην εκπαίδευση του προσωπικού που εργάζεται στα ειδικά ογκολογικά νοσοκομεία	☐	☐	☐	☐	☐	☐	☐
90	6.5 Οι γιατροί και οι νοσηλευτές στα ογκολογικά νοσοκομεία πρέπει να είναι ειδικευμένοι στην προσφορά εξατομικευμένης φροντίδας στους ασθενείς με καρκίνο π.χ.. Αξιολόγηση του πόνου, έμεση, ποιότητα ζωής	☐	☐	☐	☐	☐	☐	☐
91	7.1 Εκπαιδευτικά κέντρα πρέπει να αναπτυχθούν για να παρέχουν την ειδικότητα ογκολογικής νοσηλευτικής	☐	☐	☐	☐	☐	☐	☐
92	9.2 Η εκπαίδευση (βασική-μεταβασική-συνεχόμενη) πρέπει να βελτιωθεί για όλους τους επαγγελματίες υγείας (γιατρούς-νοσηλευτές-ψυχολόγους-κοινωνικούς λειτουργούς)	☐	☐	☐	☐	☐	☐	☐
93	9.3 Η ειδικότητα ογκολογικής νοσηλευτικής πρέπει να γίνει πραγματικότητα	☐	☐	☐	☐	☐	☐	☐
94	10.3 Οι γιατροί και οι νοσηλευτές πρέπει να παρακολουθήσουν σειρές μαθημάτων βελτίωσης της επικοινωνίας	☐	☐	☐	☐	☐	☐	☐

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
95	14.5 Οι γιατροί και οι νοσηλεύτριες πρέπει να εκπαιδευτούν κατάλληλα για να αναγνωρίζουν τα συμπτώματα του καρκίνου σε ένα αρχικό στάδιο και η διάγνωση να γίνεται το συντομότερο δυνατόν							
96	19.4 Η εκπαίδευση των νοσηλευτών και των γιατρών στην ογκολογία πρέπει να βελτιωθεί, ειδικά σε σχέση με την ψυχολογική υποστήριξη των ασθενών με καρκίνο							
97	20.6 Ευκαιρίες για βασική και μεταπτυχιακή εκπαίδευση για το προσωπικό που εργάζεται σε ογκολογικές μονάδες. Η οργάνωση εκπαιδευτικών προγραμμάτων πρέπει να έχει στόχο να εξοπλίσει το προσωπικό προκειμένου να παρέχει φροντίδα υψηλής ποιότητας							
98	23.3 Η εκπαίδευση σχετικά με την αντιμετώπιση του πόνου πρέπει να βελτιωθεί, ώστε ο πόνος να μπορεί να αντιμετωπιστεί ακόμη και στα κέντρα πρωτοβάθμιας φροντίδας (κέντρα υγείας, εξωτερικά ιατρεία, κ.λ.π.)							
99	28.1 Όλοι οι επαγγελματίες υγείας πρέπει να παρακολουθήσουν σεμινάρια επικοινωνίας							
100	10.4 Πρόληψη και αντιμετώπιση του λεμφοιδήματος από τους ειδικούς							

Ελλείψεις Προσωπικού

		1	2	3	4	5	6	7
101	3.5 Η μεγάλη έλλειψη ειδικευμένου νοσηλευτικού προσωπικού απαιτεί την άμεση επεξεργασία και την εφαρμογή ενός συνολικού σχεδίου για τη προσέλκυση και την παραμονή των νοσηλευτών στο επάγγελμα							
102	14.6 Πρέπει να προσληφθούν νοσηλευτές από το κράτος ώστε να υπερνικηθεί το πρόβλημα της έλλειψης του προσωπικού στις υπηρεσίες κατ' οίκον							
103	18.4 Ο αριθμός του νοσηλευτικού προσωπικού πρέπει να αυξηθεί στα ογκολογικά νοσοκομεία							
104	18.3 Οι ογκολογικές κλινικές πρέπει να επανδρωθούν με κοινωνικούς λειτουργούς και ψυχολόγους							
105	23.2 Η χημειοθεραπεία θα μπορούσε να γίνεται και στα Κέντρα Υγείας, εάν υπήρχε επαρκές προσωπικό και η κατάλληλη εκπαίδευση							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Ξενώνες

		1	2	3	4	5	6	7
106	12.2 Ξενώνες πρέπει να λειτουργούν κοντά στα ογκολογικά νοσοκομεία για τους ασθενείς και τους συγγενείς τους που έρχονται από μακριά							
107	27.4 Ξενώνες πρέπει να δημιουργηθούν για τους ασθενείς με καρκίνο και τους συγγενείς τους που έρχονται από μακριά για θεραπεία στα ογκολογικά νοσοκομεία							

Καταγραφή Καρκίνου

108	24.1 Καταγραφή όλων των καρκίνων							
109	29.2 Ένα πρόγραμμα καταγραφής όλων των καρκίνων σε εθνικό επίπεδο πρέπει να αναπτυχθεί							

Έρευνα

110	5.1 Πρέπει να αναπτυχθεί η βασική έρευνα όσον αφορά τον καρκίνο							
111	5.2 Πρέπει να αναπτυχθεί η εφαρμοσμένη έρευνα και η έρευνα σχετικά με μοριακές δομές προκειμένου να βελτιωθούν οι τρόποι με τους οποίους αντιμετωπίζονται οι ογκολογικοί ασθενείς							
112	6.4 Η κλινική νοσηλευτική έρευνα όσον αφορά την ογκολογία πρέπει να αναπτυχθεί προκειμένου να βελτιωθεί η παρεχόμενη φροντίδα							
113	7.2 Ερευνητικά κέντρα πρέπει να αναπτυχθούν σχετικά με την φροντίδα που παρέχεται στους ασθενείς με καρκίνο							
114	19.2 Ερευνητικές ομάδες πρέπει να διαμορφωθούν, κατευθυνόμενες από μια κεντρική επιτροπή							

Στίγμα

115	27.1 Το "στίγμα" του καρκίνου πρέπει να αντιμετωπισθεί							

Οργάνωση

116	15.2 Όλα τα νοσοκομεία πρέπει να οργανωθούν με τέτοιο τρόπο ώστε οι περισσότεροι ασθενείς με καρκίνο να μπορούν να θεραπευθούν κοντά στα σπίτια τους							
117	24.5 Προγράμματα αποκατάστασης και παρηγορητικής αγωγής πρέπει να οργανωθούν στις αστικές και αγροτικές περιοχές της Ελλάδας από ειδικά εκπαιδευμένους επαγγελματίες							

1= Πολύ χαμηλή προτεραιότητα 7=Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
118	7.3 Πρέπει να αναπτυχθούν επιτροπές για τον έλεγχο και την αξιολόγηση της φροντίδας που παρέχεται στους ασθενείς με καρκίνο							

Τεχνολογία

119	21.2 Τα γενικά νοσοκομεία της περιφέρειας πρέπει να είναι επαρκώς εξοπλισμένα ώστε η διάγνωση και η θεραπεία του καρκίνου να γίνονται εκεί, ώστε να μην υπάρχει καμία ανάγκη για τους ασθενείς να επισκέπτονται τα μεγάλα αντικαρκινικά νοσοκομεία							
120	24.4 Οι ασθενείς με καρκίνο θα μπορούσαν να έχουν τον επανέλεγχο στα Κέντρα Υγείας μετά από τη θεραπεία τους στο νοσοκομείο, με την καθοδήγηση ογκολόγων μέσω της απευθείας σύνδεσης με υπολογιστές							
121	4.1 Τα τέσσερα ογκολογικά νοσοκομεία στην Ελλάδα πρέπει να ενισχυθούν με επαρκή τεχνολογία και προσωπικό							

Λίστες Αναμονής

122	5.4 Οι λίστες αναμονής πρέπει να ελαχιστοποιηθούν για την εισαγωγή στα ογκολογικά νοσοκομεία							

Συνθήκες εργασίας

123	3.6 Οι συνθήκες εργασίας πρέπει να βελτιωθούν έτσι ώστε το στρες να είναι λιγότερο							

Ειδικές Υπηρεσίες

124	19.3 Μεγάλη προσοχή πρέπει να δοθεί στις μεταμοσχεύσεις μυελού των οστών							

Δικτύωση

125	3.3 Πρέπει να δημιουργηθούν ειδικοί χώροι στα ογκολογικά νοσοκομεία για τους νοσηλευτές, όπως γραφεία και χώροι συνάντησης, για την ανταλλαγή ιδεών και τη συζήτηση των προβλημάτων των ογκολογικών κλινικών							

1= Πολύ χαμηλή προτεραιότητα
7= Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
Εργοθεραπεία								
126	8.8 Οι ασθενείς με καρκίνο πρέπει να απασχολούνται στο νοσοκομείο εφόσον το επιτρέπει η κατάστασή τους (εργοθεραπεία)	☐	☐	☐	☐	☐	☐	☐
Εκπαίδευση								
127	8.6 Πρέπει να υπάρχει η δυνατότητα για τους νέους ασθενείς με καρκίνο να συνεχίσουν την εκπαίδευσή τους στο νοσοκομείο	☐	☐	☐	☐	☐	☐	☐
Διάφορα								
128	5.3 Οι επιτροπές ογκολογίας πρέπει να αναπτύξουν δραστηριότητες στα νοσοκομεία ογκολογίας, να μην υπάρχουν μόνο στα «χαρτιά»	☐	☐	☐	☐	☐	☐	☐
129	5.5 Η διάρκεια παραμονής των ασθενών στα ογκολογικά νοσοκομεία πρέπει να ελαχιστοποιηθεί	☐	☐	☐	☐	☐	☐	☐
130	15.3 Οι ογκολόγοι πρέπει να έχουν πρόσβαση σε βάσεις δεδομένων σχετικά με πρωτόκολλα θεραπείας έτσι ώστε οι ασθενείς με καρκίνο να μπορούν να λάβουν την καλύτερη δυνατή θεραπεία	☐	☐	☐	☐	☐	☐	☐

Appendix 7

Accompanying letter to the second round questionnaire of health care providers' Delphi study

N. Efstathiou
136 Vryoulon Str.
Kessariani
Athens
GR 16121
Tel. 7290355 (home)
6414746 (work)
e-mail: nefstath@glam.ac.uk

Athens,

Thank you for replying on the first round of this 'Delphi' study about the cancer services in Greece. One hundred and thirty suggestions were generated by all the participants. A panel analysed all the suggestions and categorised them under themes. On the second round questionnaire, included in the envelope, the suggestions are presented under these themes. I am asking you to rate these suggestions on a scale that ranges from 1 (very low priority) to 7 (very high priority).

I would be grateful if you complete and post back the questionnaire in the pre-paid envelope provided as soon as possible.

Your help for the completion of this study is immense and I would like to thank you again.

N. Efstathiou
RGN, MSc

Ν. Ευσταθίου
Βρυούλων 136
Καισαριανή
Αθήνα
16121
Τηλ.. 7290355 (σπίτι)
6414746 (εργασία)
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Αθήνα,

Σας ευχαριστώ για την επιστροφή του πρώτου γύρου αυτής της έρευνας "Δελφοί" που αφορά τις ογκολογικές υπηρεσίες στην Ελλάδα. Εκατόν τριάντα προτάσεις παρήχθησαν από όλους τους συμμετέχοντες. Μια επιτροπή ανέλυσε όλες τις προτάσεις και τις ταξινόμησε κάτω από κατηγορίες. Στο ερωτηματολόγιο του δεύτερου γύρου, που περιλαμβάνεται στο φάκελο, οι προτάσεις παρουσιάζονται κάτω από αυτές τις κατηγορίες. Σας ζητώ να βαθμολογήσετε την προτεραιότητα που θα δίνατε σε κάθε μια από αυτές τις προτάσεις στην κλίμακα που κυμαίνεται από 1 (πολύ χαμηλή προτεραιότητα) ως 7 (πολύ υψηλή προτεραιότητα).

Θα ήμουν ευγνώμων εάν συμπληρώνατε το ερωτηματολόγιο και το στέλνατε στον προπληρωμένο φάκελο το συντομότερο δυνατόν.

Η βοήθειά σας για την ολοκλήρωση αυτής της μελέτης είναι απαραίτητη και θα επιθυμούσα να σας ευχαριστήσω πάλι.

Ν. Ευσταθίου
Νοσηλευτής, MSc

Appendix 8

The third round questionnaire for healthcare providers

Nikolaos Efstathiou
136 Vryoulon str.
Kessariani
Athens
GR 16121

University of Glamorgan
School of Nursing & Midwifery
Pontypridd
CF37 1DL
Wales, UK

3rd ROUND

The 'Delphi' Technique in the Study of Oncology Services in Greece

How to complete the questionnaire:

In the following groups of suggestions, rank in order the suggestions within each group. Provide no 1 for the most desirable suggestion, no 2 for the next more desirable etc.

By this way the most important suggestions within each group will emerge.

Panel no ☐☐

A45

'Manpower Resources'

Statements	Rank in order
The shortage of specialised nursing staff requires the immediate initiation and application of a plan for the recruitment and retaining of nurses in the profession	
Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services	
The number of nursing staff should be increased in oncology hospitals	
Oncology wards should be staffed with social worker and psychologist	
Health centres should employ nurses so that home care services may be provided to the community around the health centres	
Services like home care should be provided by doctors, nurses and social workers	

'Organisational Issues'

Statements	Rank in order
There should be wiser financial arrangements so money will not be wasted. Money should be spent wisely for equipment and machinery necessary for the treatment of cancer patients	
A registration programmes of all the cancers on national level must be developed	
Oncology hospitals must become independent, functional, efficient, non beurocratic and human. The environment of oncology hospitals should not seem impersonal	
The system connecting the health centres with the hospitals should be improved	

' Public Health / Health Promotion / Prevention'

Statements	Rank in order
Media should inform people about cancer prevention	
Cancer prevention programmes must be developed with the co-operation of all health professionals	
Screening services in hospitals should be working more hours, so that waiting lists may get shorter (waiting period for mammography may take 4 months)	

'Development of services'

Statements	Rank in order
Day units should be developed as well as special intensive care units, physiotherapy units and home care services in all the oncology hospitals	
Home care services should be provided by all oncology centres.	
Home care should be developed for oncology patients not only during treatment but for terminally ill patients	
Day units should be increased in oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients may remain more in their home environment	
Pain management services should be developed by pain clinics, offering pain management not only during treatment but whilst staying at home, through all the stages of the disease	

'Equity in Access of health care'

Statements	Rank in order
Cancer hospitals should be built in the greater area of Greece so that cancer patients won't have to travel far for special treatment	
Insurance companies should cover cancer patients during all the phases of the disease (diagnosis, treatment, rehabilitation)	
Doctors in oncology hospitals and nurses should be specialised to offer personalised care to cancer patients, e.g. pain management, vomiting, quality of life	

'Education / Training'

Statements	Rank in order
Emphasis should be given to staffs' education in special oncology hospitals.	
Educational centres must be developed providing an oncology nursing specialty.	
Education (basic, post basic and continuing) must be improved for all health professionals (doctors, nurses, psychologists, social workers)	
Doctors and nurses should be educated so that they can recognise cancer symptoms in an early stage and diagnosis may be made as soon as possible	
There should be opportunities for basic and post basic education for all health professionals in oncology wards. Education programmes should be organised as well and nurses should have the opportunity to take part in order to improve the provision of nursing care	

'Psychological Support'

Statements	Rank in order
Psychological support should be given by professionals not only on diagnosis but during treatment too	
Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist and social workers	
Psychological support groups must be created for the support of patients and families not only in the hospital but in the community as well	
Psychological support should be provided to cancer patients and their families through all the stages of the disease	
Psychological support for nurses working in oncology wards. Support groups must be created by nurses for nurses in conjunction with counselors	

'Communication/Working conditions/Patient education'

Statements	Rank in order
Doctors and nurses must get communication improvement courses	
All health professionals should attend seminars on communication skills	
All health professionals who come in contact with cancer patients should receive special training in communication skills (how to tell the diagnosis, bad news regarding treatment, etc.)	
There should be the possibility for young cancer patients to continue their education in the hospital	
Working conditions must be improved so that working in a hospital becomes less stressful	

'Palliative Care / Pain Management'

Statements	**Rank in order**
Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life	
Development of terminal care for the patients either at home or in special hospitals and institutions	
Great attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics.	

Ν. Ευσταθίου
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3ος ΓΥΡΟΣ

Η Τεχνική 'Δελφοί' στην Έρευνα για τις Ογκολογικές Υπηρεσίες στην Ελλάδα

Πώς να συμπληρώσετε το ερωτηματολόγιο:

Ξεχωριστά για κάθε ομάδα προτάσεων που ακολουθεί ιεραρχείστε τις προτάσεις, τοποθετώντας τον αριθμό 1 για την πιό επιθυμητή πρόταση, τον αριθμό 2 για την επόμενη πιό επιθυμητή κ.λπ.

Με αυτόν τον τρόπο θα ξεχωρίσουν οι σημαντικότερες προτάσεις μέσα σε κάθε ομάδα.

Panel no

'Ελλείψεις Προσωπικού'

Προτάσεις	Ιεραρχείστε
Η μεγάλη έλλειψη ειδικευμένου νοσηλευτικού προσωπικού απαιτεί την άμεση επεξεργασία και την εφαρμογή ενός συνολικού σχεδίου για τη προσέλκυση και την παραμονή των νοσηλευτών στο επάγγελμα	
Πρέπει να προσληφθούν νοσηλευτές από το κράτος ώστε να υπερνικηθεί το πρόβλημα της έλλειψης του προσωπικού στις υπηρεσίες κατ' οίκον	
Ο αριθμός του νοσηλευτικού προσωπικού πρέπει να αυξηθεί στα ογκολογικά νοσοκομεία	
Οι ογκολογικές κλινικές πρέπει να επανδρωθούν με κοινωνικούς λειτουργούς και ψυχολόγους	
Τα Κέντρα Υγείας πρέπει να προσλάβουν νοσηλεύτριες ώστε οι υπηρεσίες κατ' οίκον νοσηλείας να μπορούν να παρασχεθούν στην κοινότητα γύρω από τα Κέντρα Υγείας	
Υπηρεσίες όπως η κατ' οίκον νοσηλεία πρέπει να προσφέρονται από τους γιατρούς, τις νοσηλεύτριες και τους κοινωνικούς λειτουργούς	

'Θέματα Οργάνωσης'

Προτάσεις	Ιεραρχείστε
Προσεκτικές οικονομικές ρυθμίσεις πρέπει να γίνουν ώστε να μην σπαταλούνται χρήματα. Τα χρήματα πρέπει να ξοδεύονται σοφά για εξοπλισμό και μηχανήματα που είναι απαραίτητα για τη θεραπεία των ασθενών με καρκίνο	
Ένα πρόγραμμα καταγραφής όλων των καρκίνων σε εθνικό επίπεδο πρέπει να αναπτυχθεί	
Τα ογκολογικά νοσοκομεία πρέπει να είναι ανεξάρτητα, λειτουργικά, αποδοτικά, μη- γραφειοκρατικά, χωρίς το περιβάλλον να θυμίζει ίδρυμα.. Το περιβάλλον των ογκολογικών νοσοκομείων δεν πρέπει να φέρνει στο μυαλό ένα απρόσωπο ίδρυμα	
Το σύστημα που συνδέει τα Κέντρα Υγείας με τα νοσοκομεία πρέπει να βελτιωθεί	

' Δημόσια Υγεία / Προαγωγή Υγείας / Πρόληψη'

Προτάσεις	Ιεραρχείστε
Τα media πρέπει να παρέχουν πληροφορίες στον κόσμο για την πρόληψη του καρκίνου	
Πρέπει να αναπτυχθούν προγράμματα πρόληψης του καρκίνου με τη συνεργασία όλων των επαγγελματιών υγείας	
Οι υπηρεσίες προληπτικού ελέγχου στα νοσοκομεία πρέπει να λειτουργούν περισσότερες ώρες, έτσι ώστε οι λίστες αναμονής να είναι μικρότερες (η περίοδος αναμονής για μια μαστογραφία μπορεί να πάρει 4 μήνες)	

'Ανάπτυξη Υπηρεσιών'

Προτάσεις	Ιεραρχείστε
Μονάδες ημερήσιας νοσηλείας πρέπει να αναπτυχθούν καθώς επίσης και ειδικές μονάδες εντατικής παρακολούθησης, μονάδες φυσιοθεραπείας και υπηρεσίες κατ' οίκον νοσηλείας σε όλα τα νοσοκομεία ογκολογίας	
Υπηρεσίες οικιακής φροντίδας από όλα τα νοσοκομεία ογκολογίας	
Η κατ' οίκον νοσηλεία πρέπει να αναπτυχθεί για τους ασθενείς με καρκίνο όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και για τους ασθενείς τελικού σταδίου	
Οι μονάδες ημερήσιας νοσηλείας πρέπει να αυξηθούν στα ογκολογικά νοσοκομεία προκειμένου να εξυπηρετηθούν περισσότεροι ασθενείς με καρκίνο (μονάδες ημέρας, ακτινοθεραπεία των εξωτερικών ασθενών), ώστε οι ασθενείς να μένουν περισσότερο στο οικογενειακό περιβάλλον τους	
Αντιμετώπιση του πόνου από τις κλινικές πόνου, προσφέροντας αντιμετώπιση του πόνου όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και στο σπίτι, σε όλα τα στάδια της ασθένειας	

'Ιση Πρόσβαση σε Υπηρεσίες Υγείας'

Προτάσεις	Ιεραρχείστε
Ογκολογικά νοσοκομεία πρέπει να χτιστούν στη ευρύτερη περιοχή της Ελλάδας έτσι ώστε οι ασθενείς με καρκίνο να μην χρειάζεται να ταξιδεύουν μακριά για ειδικές θεραπείες	
Οι ασφαλιστικές εταιρείες πρέπει να καλύπτουν τους ασθενείς με καρκίνο κατά τη διάρκεια όλων των φάσεων της ασθένειας (διάγνωση-θεραπεία-αποκατάσταση)	
Οι γιατροί και οι νοσηλευτές στα ογκολογικά νοσοκομεία πρέπει να είναι ειδικευμένοι στην προσφορά εξατομικευμένης φροντίδας στους ασθενείς με καρκίνο π.χ.. Αξιολόγηση του πόνου, έμεση, ποιότητα ζωής	

'Εκπαίδευση / Κατάρτιση '

Προτάσεις	Ιεραρχείστε
Έμφαση πρέπει να δοθεί στην εκπαίδευση του προσωπικού που εργάζεται στα ειδικά ογκολογικά νοσοκομεία	
Εκπαιδευτικά κέντρα πρέπει να αναπτυχθούν για να παρέχουν την ειδικότητα ογκολογικής νοσηλευτικής	
Η εκπαίδευση (βασική-μεταβασική-συνεχόμενη) πρέπει να βελτιωθεί για όλους τους επαγγελματίες υγείας (γιατρούς-νοσηλευτές-ψυχολόγους-κοινωνικούς λειτουργούς)	
Οι γιατροί και οι νοσηλεύτριες πρέπει να εκπαιδευτούν κατάλληλα για να αναγνωρίζουν τα συμπτώματα του καρκίνου σε ένα αρχικό στάδιο και η διάγνωση πρέπει να γίνεται το συντομότερο δυνατόν	
Ευκαιρίες για βασική και μεταπτυχιακή εκπαίδευση για το προσωπικό που εργάζεται σε ογκολογικές μονάδες. Η οργάνωση εκπαιδευτικών προγραμμάτων πρέπει να έχει στόχο να εξοπλίσει το προσωπικό προκειμένου να παρέχει φροντίδα υψηλής ποιότητας	

'Ψυχολογική Υποστήριξη'

Προτάσεις	Ιεραρχείστε
Ψυχολογική υποστήριξη πρέπει να παρέχεται από τους επαγγελματίες όχι μόνο κατά τη διάγνωση αλλά και κατά τη διάρκεια της θεραπείας	
Ομάδες ψυχολογικής υποστήριξης πρέπει να δημιουργηθούν στα ογκολογικά νοσοκομεία, και να αποτελούνται από ψυχίατρο, νοσηλεύτριες, ψυχολόγο και κοινωνικούς λειτουργούς	
Ομάδες ψυχολογικές υποστήριξης πρέπει να δημιουργηθούν για την υποστήριξη των ασθενών και των οικογενειών τους όχι μόνο στο νοσοκομείο αλλά και στην κοινότητα	
Ψυχολογική υποστήριξη πρέπει να παρέχεται στους ασθενείς με καρκίνο και τις οικογένειές τους σε όλα τα στάδια της ασθένειας	
Ψυχολογική υποστήριξη για τους νοσηλευτές που εργάζονται σε ογκολογικές μονάδες. Οι ομάδες υποστήριξης πρέπει να δημιουργηθούν από τους νοσηλευτές για τους νοσηλευτές σε συνεργασία με ειδικούς συμβούλους	

'Επικοινωνία / Συνθήκες Εργασίας / Εκπαίδευση Ασθενών'

Προτάσεις	Ιεραρχείστε
Οι γιατροί και οι νοσηλευτές πρέπει να παρακολουθήσουν σειρές μαθημάτων βελτίωσης της επικοινωνίας	
Όλοι οι επαγγελματίες υγείας πρέπει να παρακολουθήσουν σεμινάρια επικοινωνίας	
Όλοι οι επαγγελματίες υγείας που έρχονται σε επαφή με τους ασθενείς με καρκίνο πρέπει να λαμβάνουν ειδική κατάρτιση όσον αφορά την επικοινωνία (πώς να ανακοινώνεται η διάγνωση, δυσάρεστες ειδήσεις σχετικά με τη θεραπεία, κ.λπ...)	
Πρέπει να υπάρχει η δυνατότητα για τους νέους ασθενείς με καρκίνο να συνεχίσουν την εκπαίδευσή τους στο νοσοκομείο	
Οι συνθήκες εργασίας πρέπει να βελτιωθούν έτσι ώστε το στρες να είναι λιγότερο	

'Παρηγορητική Φροντίδα / Αντιμετώπιση του Πόνου'

Προτάσεις	Ιεραρχείστε
Υπηρεσίες σαν την κατ' οίκον νοσηλεία πρέπει να αναπτυχθούν για τους αρρώστους τελικού σταδίου με καρκίνο, για καλύτερη ποιότητα ζωής στα τελευταία στάδια της ζωής	
Ανάπτυξη της παρηγορητικής φροντίδας για τους ασθενείς είτε στο σπίτι είτε στα ειδικά νοσοκομεία και τα ιδρύματα	
Μεγάλη προσοχή πρέπει να δοθεί στην αντιμετώπιση του πόνου. Οι επαγγελματίες υγείας πρέπει να ενημερώνονται και να εκπαιδεύονται στην αντιμετώπιση του πόνου. Κλινικές πόνου	

Appendix 9

Accompanying letter to the third round questionnaire of health care providers' Q- Delphi study

N. Efstathiou
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Kessariani
Athens
GR 16121
Τηλ. 7290355
6414746

Athens,

I would like to thank those who completed the second round questionnaire for the cancer services in Greece.

After analysing the data, 39 out of the 130 suggestions in the second round questionnaire had a mean score of six and above (the range of the scale was from 1 'very low priority' to 7 'very high priority') and none of the respondents rated them below 4. Those 39 suggestions were grouped again under categories that were suggested by the same panel who analysed the first round and now form the third round questionnaire.

I would like to ask you to rank in order these 39 suggestions within each group, according to how important you think they are. By this way the most important suggestions will emerge.

The response rate for round two was 74% and I hope for the same response rate and even more. Even those who did not send back the second round questionnaire can still participate in this round. If you have any queries regarding the completion of this round questionnaire do not hesitate to communicate with me.

I would be grateful if you complete the questionnaire and send it back in the pre-paid envelope provided. I would like to thank you in advance.

Yours sincerely,
N. Efstathiou
RGN, MSc

Ν. Ευσταθίου
Βρυούλων 136
Καισαριανή
Αθήνα
16121
Τηλ. 7290355
6414746

Αθήνα,

Θα επιθυμούσα να ευχαριστήσω εσας που συμπληρώσατε το ερωτηματολόγιο του δεύτερου γύρου για τις ογκολογικές υπηρεσίες στην Ελλάδα.

Μετά από την ανάλυση των δεδομένων, 39 από τις 130 προτάσεις στο δεύτερο ερωτηματολόγιο είχαν μέσο όρο έξι και ανω (η κλίμακα ήταν από 1 "πολύ χαμηλή προτεραιότητα" μέχρι 7 "πολύ υψηλή προτεραιότητα") και κανένας από τους ερωτωμένους δεν τις εκτίμησε κάτω από 4. Οι 39 αυτές προτάσεις ομαδοποιήθηκαν πάλι κάτω από κατηγορίες που προτάθηκαν από την ίδια επιτροπή που ανέλυσε τον πρώτο γύρο και αποτελούν τώρα το εοωτηματολόγιο του τρίτου γύρου.

Θα ήθελα να σας ζητήσω να ιεραρχήσετε αυτές τις 39 προτάσεις μέσα σε κάθε ομάδα, σύμφωνα με πόσο σημαντικές νομίζετε ότι είναι. Με αυτόν τον τρόπο οι σημαντικότερες προτάσεις θα προκύψουν.

Το ποσοστό επιστροφής για τον δεύτερο γύρο ήταν 74% και ελπίζω για το ίδιο ποσοστό και ακόμα περισσότερο. Ακόμη και εκείνοι που δεν έστειλαν το δεύτερο ερωτηματολόγιο μπορούν να συμμετέχουν σε αυτόν τον γύρο. Εάν έχετε οποιεσδήποτε ερωτήσεις σχετικά με την συμπλήρωση αυτού του ερωτηματολογίου μην διστάσετε να επικοινωνήσετε μαζί μου.

Θα ήμουν ευγνώμων εάν συμπληρώνατε το ερωτηματολόγιο και το επιστρέφατε στον προπληρωμένο φάκελο. Θα επιθυμούσα να σας ευχαριστήσω εκ των προτέρων.

Με εκτίμηση,
Ν. Ευσταθίου

Appendix 10

Accompanying letter to first round questionnaire of healthcare users' Q-Delphi study

N. Efstathiou
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Athens
GR 16121
Tel. 7290355 (home)
6414746 (work)
e-mail: nefstath@glam.ac.uk

Athens,

I would like to thank you for accepting to participate, after receiving the relevant information, in this study for the cancer services and the areas of cancer care that need to be developed or improved in Greece. This study is part of my PhD thesis that is supervised by the University of Glamorgan, School of Care Sciences, Wales UK.

So far, the first part of the project has been completed, which was the same study with health professionals. However, cancer patients and their carers, who use cancer services, should have their views heard as well. For this reason your opinion is necessary.

Your participation is very important and I hope that the method that is used to collect the data will keep you interested until the completion of the study.

In this envelope you will find a flyer regarding the study and the 'Delphi' technique. You will also find the question for round one and space to write your suggestions (maximum 5).

I would be grateful if you write your suggestions as soon as possible and post them in the pre-paid envelope that is provided. I would like to thank you in advance and I am waiting for your replies.

PS. THE RETURN OF THE QUESTIONNAIRE IMPLIES YOUR AGREEMENT TO PARTICIPATE IN THIS STUDY

Yours sincerely,
N. Efstathiou
RGN, MSc

A61

Ν. Ευσταθίου
Βρυούλων 136
Καισαριανή
Αθήνα
16121
Τηλ. 7290355 (σπίτι)
6414746 (εργασία)
nefstath@glam.ac.uk

Αθήνα,

Θα ήθελα να σας ευχαριστήσω για την αποδοχή να συμμετάσχετε, μετά από τις σχετικές πληροφορίες που λάβατε, σε αυτήν την μελέτη για τις ογκολογικές υπηρεσίες και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να αναπτυχθούν ή να βελτιωθούν στην Ελλάδα. Αυτή η μελέτη είναι μέρος της διδακτορικής διατριβής μου που εποπτεύεται από το University of Glamorgan, School of Care Sciences, Ουαλία, Μεγάλη Βρετανία.

Μέχρι τώρα, έχει σχεδόν ολοκληρωθεί το πρώτο μέρος της μελέτης, που αφορά τις απόψεις των επαγγελματιών υγείας. Οι ασθενείς με καρκίνο και αυτοί που τους φροντίζουν χρησιμοποιούν τις ογκολογικές υπηρεσίες και πρέπει να προβάλουν τις απόψεις τους. Για αυτόν τον λόγο η άποψή σας είναι απαραίτητη.

Η συμμετοχή σας είναι πολύ σημαντική και ελπίζω ότι η μέθοδος που χρησιμοποιείται για να συλλέξει τα δεδομένα θα σας κρατήσει σε ενδιαφέρον μέχρι την ολοκλήρωση της μελέτης.

Σε αυτόν τον φάκελο θα βρείτε ένα φυλάδιο σχετικά με την έρευνα και την τεχνική "Δελφοί". Θα βρείτε επίσης ένα φύλο με την ερώτηση του πρώτου γύρου και το διάστημα για να γράψετε τις προτάσεις σας (το πολύ 5).

Θα ήμουν ευγνώμων εάν γράφατε τις προτάσεις σας το συντομότερο δυνατόν και τις στέλνατε στον προπληρωμένο φάκελο που παρέχεται. Θα επιθυμούσα να σας ευχαριστήσω εκ των προτέρων και περιμένω τις απαντήσεις σας.

Η ΕΠΙΣΤΡΟΦΗ ΤΟΥ ΕΡΩΤΗΜΑΤΟΛΟΓΙΟΥ ΥΠΟΝΟΕΙ ΤΗΝ ΑΠΟΔΟΧΗ ΣΑΣ ΓΙΑ ΣΥΜΜΕΤΟΧΗ ΣΕ ΑΥΤΗΝ ΤΗΝ ΜΕΛΕΤΗ

Με εκτίμηση,
Ν. Ευσταθίου

Appendix 11

Leaflet giving information on Delphi technique to participants of the healthcare users' Delphi study

References and bibliography

- Crotty M. (1993) The emerging role of the British nurse teacher in Project 2000 programmes: A Delphi survey. *Journal of Advanced Nursing*, 18, 150-157

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- Papastavrou E. (1996) Delphi technique as a method for nursing research: Critical analysis. *Nosileftiki*, 35 (3), 180-186 (in Greek)

If you would like to have more information on the project or on Delphi technique do not hesitate to contact me:

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THE SCHOOL OF NURSING & MIDWIFERY

UNIVERSITY OF GLAMORGAN

The Use of 'Delphi' Technique in the Study of Oncology Services in Greece

INFORMATION ABOUT THE PROJECT

AIM OF THE STUDY

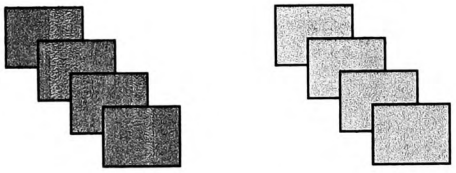
To develop consensus among a group of experts on the cancer services and the areas of cancer care that need to be developed or improved in Greece

HOW 'DELPHI' TECHNIQUE WORKS

- Questionnaires are used (usually three rounds) in order to achieve consensus among the participants
- The participants are provided with feedback from the whole group's responses
- It provides the participants the opportunity to reformulate their opinions with the knowledge of the group's viewpoint in mind

WHEN THE USE OF 'DELPHI' TECHNIQUE IS NECESSARY

- In cases where information is needed for issues that we do not know a lot
- In defining concepts and priorities (Mead, 1993)



THE GROUP OF EXPERTS IN THIS STUDY

- Cancer patients and carers of cancer patients treated either in general or special cancer hospitals

(The same type of study has been completed with healthcare providers)

'Delphi' technique seemed appropriate for this study of cancer services and the areas of cancer care that need to be improved in Greece

ADVANTAGES OF 'DELPHI' TECHNIQUE

- It offers anonymity
- It decreases the domination of certain members in the group
- There is no fear of expressing views due to the presence of different persons in the same group
- The cost and time afforded is less if the members of the group had to meet
- It permits greater geographical representation

Βιβλιογραφία

- Crotty M. (1993) The emerging role of the British nurse teacher in Project 2000 programmes: A Delphi survey. *Journal of Advanced Nursing*, 18, 150-157
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- Mead D. (1993) *The development of primary nursing in National Health Service care giving institutions in Wales*. Unpublished Thesis. University of Wales
- Παπασταύρου Ε. (1996) Η τεχνική 'Δελφοί' στη μεθοδολογία της νοσηλευτικής έρευνας: Κριτική ανάλυση. Νοσηλευτική, 35 (3): 180-186

Εάν θα επιθυμούσατε να έχετε περισσότερες πληροφορίες για την έρευνα ή για την τεχνική 'Δελφοί' μην διστάστε να επικοινωνήσετε μαζί μου:

Νικόλοαος Ευσταθίου
Νοσηλευτής, MSc
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THE SCHOOL OF NURSING & MIDWIFERY

UNIVERSITY OF GLAMORGAN

Η Τεχνική 'Δελφοί' στην έρευνα για τις ογκολογικές υπηρεσίες στην Ελλάδα

ΠΛΗΡΟΦΟΡΙΕΣ ΓΙΑ ΤΗΝ ΕΡΕΥΝΑ

ΣΚΟΠΟΣ ΤΗΣ ΕΡΕΥΝΑΣ

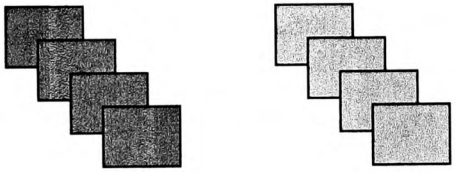
Να αναπτύξει τη συναίνεση μιας ομάδας εμπειρογνωμόνων για τις ογκολογικές υπηρεσίες και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να αναπτυχθούν ή να βελτιωθούν στην Ελλάδα

ΠΩΣ ΛΕΙΤΟΥΡΓΕΙ Η ΤΕΧΝΙΚΗ "ΔΕΛΦΟΙ"

- Χρησιμοποιούνται διαδοχικά ερωτηματολόγια (συνήθως τρεις γύροι) προκειμένου να επιτευχθεί συναίνεση μεταξύ των συμμετεχόντων
- Παρέχεται η δυνατότητα επανατροφοδότησης των απαντήσεων ολόκληρης της ομάδας
- Παρέχει στους συμμετέχοντες την ευκαιρία να αλλάξουν τις απόψεις τους βασιζόμενοι στη γνώση των απόψεων της ομάδας

ΠΟΤΕ ΕΙΝΑΙ ΑΠΑΡΑΙΤΗΤΗ Η ΧΡΗΣΗ ΤΗΣ ΤΕΧΝΙΚΗΣ "ΔΕΛΦΟΙ"

- Σε περιπτώσεις όπου απαιτείται πληροφόρηση σε ζητήματα για τα οποία δεν γνωρίζουμε πολλά
- Κατά τον ορισμό εννοιών και τον προσδιορισμό προτεραιοτήτων (Mead, 1993)



Η ΟΜΑΔΑ ΕΜΠΕΙΡΟΓΝΩΜΟΝΩΝ ΣΕ ΑΥΤΗΝ ΤΗΝ ΜΕΛΕΤΗ

- Ασθενείς με καρκίνο και οι συγγενείς τους που έχουν λάβει θεραπεία είτε σε γενικά είτε σε ειδικά ογκολογικά νοσοκομεία

(Ο ίδιος τύπος μελέτης έχει προηγηθεί με επαγγελματίες υγείας)

Η τεχνική "Δελφοί" φαίνεται ότι είναι κατάλληλη για την μελέτη των ογκολογικών υπηρεσιών και τους τομείς της ογκολογικής φροντίδας που χρειάζεται να βελτιωθούν στην Ελλάδα

ADVANTAGES OF 'DELPHI' TECHNIQUE

- Προσφέρει ανωνυμία
- Μειώνει την κυριαρχία ορισμένων μελών στην ομάδα
- Δεν υπάρχει κανένας φόβος στην έκφραση των απόψεων λόγω της παρουσίας διαφορετικών επαγγελματιών στην ίδια ομάδα
- Μειώνεται το κόστος και ο χρόνος που θα χρειαζόταν για τη συνάντηση μιας ομάδας
- Επιτρέπει μεγαλύτερη γεωγραφική εκπροσώπηση όσον αφορά τους συμμετέχοντες

Appendix 12

The second round questionnaire for healthcare users

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2nd ROUND

The 'Delphi' Technique in the Study of Oncology Services in Greece

How to complete the questionnaire:

Tick the box that describes best your opinion on the priority you would give to the suggestions that follow.

The scale ranges from 'very low priority' (no 1)
'low priority' (no 2);
'medium low priority' (no 3);
'neither low nor high priority' (no 4);
'medium high priority' (no 5);
'high priority' (no 6) and
'very high priority' (no7).

Panel no

1 = Very low priority
7 = Very high priority

Communication

		1	2	3	4	5	6	7
1	3,2 The anouncement of cancer diagnosis should be done in a better way							
2	19,7 Doctors and nurses do not have the proper education to face such "delicate" diseases. Improvement in communication is needed							
3	25,5 The nursing staff a lot of times is not aware of what the patient knows about his disease, and they act as if they do not know what the patient has							
4	29,1 The nursing staff should know the patients they nurse, they should not ask the patients the same the same questions all the time							

Day units

5	13,1 Day clinics							
6	18,2 Day clinics should be developed, the existing beds are not enough							

Education / Training

7	9,3 Educated nurses							
8	11,2 Additional education for nurses who administer chemotherapy in order not to destroy patients' hands with the toxic drug							
9	19,1 The nursing staff in general hospitals is uninterested and they are not educated to treat cancer patients							
10	20,2 The medical and nursing staff must be very sensitive regarding the timely recognition of special cancer symptoms							
11	23,1 The nursing staff in general hospitals do not seem to have the proper education regarding the disease. Improvement is neede in communication							
12	24,1 General doctors should be properly educated so that they can recognise the first symptoms of cancer							
13	25,3 All the doctors should be aware of cancer symptoms, in order to diagnose cancer early, at its beginning							

1 = Very low priority
7 = Very high priority

			1	2	3	4	5	6	7
14	26,2	Oncologists have a high level of scientific education, but money should be supplied for further education in cancer centres abroad							
15	26,5	The nursing staff should be sent abroad, at least once a year, for further education							
16	27,3	Doctors and nurses who work in special cancer centres should be properly educated							
17	29,4	Doctors and nurses should be more careful when they give chemotherapy as there happen a lot of mistakes and the drugs are toxic							
		Extra beds							
18	19,3	They should not leave the patients in the corridors for hours or even days, having as result the physical and psychological exhaustion of the patients							
19	25,2	The Greek state should give more attention in the area of health, patients should not be nursed in the corridors							
		Finance							
20	6,3	Free drug provision by all insurance companies							
21	25,6	Better provision of services by the insurance companies. Some of them offer too little							
		Home care							
22	7,1	There should exist home care (for blood tests, treatment, catheter changing, etc.)							
23	21,3	Expantion of home care so that patients may die in their known environment, with dignity and the love of their relatives							
24	22,3	More organised home care and better quality of care for the cancer patient							
25	23,4	Home care would be helpful for a lot of patients in order not to fill the hospital beds							
26	29,3	Home care should be developed, in order that cancer patients do not have to be admitted for the simpliest things							

1 = Very low priority
7 = Very high priority

Hospices

			1	2	3	4	5	6	7
27	6,1	Special places for the terminally ill who need special care							
28	7,2	There should be special places for patients who are in the final stages of the disease, who need special care							
29	23,2	The treatment of cancer patients in the final stages should be offered in special institutions, because in the hospitals they do not get the appropriate attention							
30	30,4	Special institutions should be created for cancer patients at the final stages, in order not to be nursed in the hospitals where they do not get any attention							

Hospital environment

31	15,2	The hospital buildings are miserable							
32	29,2	The day clinics should be more pleasant							

Information

33	7,3	National information net							
34	9,2	More information to relatives by the oncologists							
35	10,2	Information by the doctor reagrding the disease							
36	11,4	Honest information by the doctors, because knowledge is power							
37	23,3	The proper information by all should decharacterise cancer as a death sentence							
38	24,3	Detailed information to the patient regarding treatments available and their results							
39	24,4	Complete information to the patient and close relatives regarding the diagnosis, treatment, potential complications							
40	25,4	The information that patients get is insufficient. There should be other services that would give extra information to patients							
41	26,4	The patient should be fully informed about the process of his disease without lies							
42	27,2	Patients should be fully informed about their disease and the status of their health							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
43	30,2 Information about the disease. The diagnosis should be told to the patient, and this should be done in the best way							
	Networking							
44	26,6 There should be a kind of place where all the oncologists could meet and exchange views and information							
	New treatment							
45	26,1 New ways of treatment should be found, more effective							
	Organisation							
46	3,3 There is no organisation in general hospitals for the treatment of cancer patients, so cancer patients are transfered from hospital to hospital							
47	4,2 Organised provision of cancer care services, so that cancer patients are not transfered from hospital to hospital for examinations and special treatments							
48	14,1 Cancer patients' tests should be completed where they are nursed, so that they do not have to be transfered in other hospitals							
49	14,4 Tests and in particular biopsies should be completed faster, giving priority to patients who need treatment faster							
50	15,1 There is a lack of total treatment (laboratory support) in hospital that provide cancer services							
51	18,4 In the area of exams by special machiery I asked for an appointment in July and they could only make it in December							
52	21,1 Timely diagnosis. Fast services regarding laboratory tests (for example cytology tests take a long time)							
53	27,4 Better allocation of the CAT scans and all the special equipment and not consolidation in Athens and Thessaloniki							

1 = Very low priority
7 = Very high priority

Pain management

			1	2	3	4	5	6	7
54	2,1	Better pain management							
55	19,5	The procedure of supplying opioid analgesics to patients must be improved							
56	20,3	Pain clinics							
57	21,4	Better organisation of the pain clinics and not just the application of patches and nothing else							
58	22,5	Organosis and employment of the appropriate staff in the pain clinics for quality of life							
59	24,2	There should be pain clinics in all the hospitals for the complete pain relief							

Psychological support

60	1,3	Great lack of psychological support during treatment							
61	2,2	Psychological support for the patient and close relatives							
62	4,1	Information and psychological support							
63	8,2	Psychological support, not in a pampering way. cancer patients should be helped to accept their problem and manage it							
64	10,1	Psychological support during treatment and after discharge							
65	11,1	Psychological support should be offered and there should be social workers in every hospital to give information to patients and their relatives and encourage them							
66	13,3	Psychological support and rehabilitation units							
67	16,4	Psychological support should be offered to the members of the patient's family							
68	19,2	The nursing staff in general hospitals do not offer any kind of psychological support neither to patient nor their relatives							
69	22,4	Cancer units should be staffed with psychologist and psychiatrist who in collaboration with the oncologist they will help the patient to accept his disease							

1 = Very low priority
7 = Very high priority

			1	2	3	4	5	6	7
70	30,1	Psychological support by doctors and nurses. They should spend more time with the patients							
		Public health / Health promotion							
71	10,5	Preventive information through leaflets, radio and tv programmes, meetings							
72	11,3	Prevention, which is the most important. They should urge women with leaflets to get examined in time							
73	16,3	The prevention programmes must be developed and improved							
74	20,1	The area of public information regarding high risk groups, causes and early signs of cancer, needs to be improved							
75	21,2	Public education and information regarding the immediate recognition of the disease's symptoms							
76	22,1	Public education and sensitisation for routinely check ups at appropriate centres (like breast clinics) from the media							
77	22,2	Organosis by diferrent institutions (eg. church, committees, etc.) of talkings, information giving meetings, in order to increase prevention outcomes and detect cancer early							
78	28,1	Media should participate more in the war against cancer							
		Research							
79	12,2	Better research and effort for the treatment of the disease every day							
80	28,3	Research should be done in order to find better ways to treat chemotherapy side effects							
		Resources							
81	1,1	Diagnostic laboratories should be working extra hours so that waiting lists are not geting too long							
82	1,4	The nursing staff should be increased							
83	2,3	Creation of special units or hospitals for terminally ill patients							

1 = Very low priority
7 = Very high priority

		1	2	3	4	5	6	7
84	5,1 District development with specialised personnel, medical and nursing, on cancer matters							
85	5,2 Hospitals should be built in the district areas, but in the existing ones cancer units should be developed							
86	5,3 There are not doctors in the district, in the radiology units, who would afford time for cancer patients							
87	8,1 First of all, there should be enough space, because it is not fair for 16 patients to be in the same room, and it is depressing for somebody at the begining of the disease to watch somebody in the last stages							
88	9,1 Improvement of the wards. Less beds in the rooms							
89	9,4 Every service regarding cancer should be developed and the ones that exist should be improved							
90	27,5 The Greek state should show more interest in the organisation of cancer services							
91	28,4 The hospitals should be improved							
	Satisfaction							
92	17,1 My views regarding the staff and the place of treatment are positive							
	Special cancer units							
93	9,5 Cancer centres should be created in the district, so that patients won't have to travel far							
94	10,3 Appropriate places for chemotherapy treatment							
95	10,4 There should be the appropriate rooms and wards in the hospitals for cancer patients and hospitals should provide artificial body parts							
96	13,2 Oncology units in all the hospitals							
97	23,5 Cancer units should be developed in the district so that patients are not transfered without a good reason							
98	28,2 Cancer units should be created in general hospitals for the most common cancers, with the appropriate personnel							

1 = Very low priority
7 = Very high priority

			1	2	3	4	5	6	7
99	28,5	Cancer centres should be built in the district, so that patients with special needs won't have to travel to Athens or Thessaloniki							
		Staff attitude							
100	1,2	Doctors should give more attention and provide more time for the examination of the patients							
101	3,5	Better attitude by the medical staff							
102	8,4	Better attitude from doctors and nurses							
103	12,1	More care and love for the patients							
104	14,3	Nurses should show their understanding regarding the potential cancer patients' bad attitude, who, feeling bad about their situation, react in a strange way							
105	19,6	A lot of doctors do not inspire the feeling of trust to the patients and their relatives, so patients prefer to go abroad for better diagnosis and treatment							
		Staff shortages							
106	18,1	In the chemotherapy unit I was the personell was very helpful, but they are not enough							
107	18,3	The medical staff are great scientists with sensitivity and comprehension, but they are not enough, having as result delayed appointments							
108	22,7	Specialised medical and nursing staff should be increased							
109	25,1	The nursing staff must be increased in order to offer quality services							
110	30,3	The nursing staff must be increaased and all the vacancies must be covered							
		Staff skills							
111	14,2	Nurses should treat cancer patients like all the other patients, making them feel comfortable and forget their problem							
		Stigma							
112	27,1	The stigma of cancer should not exist							

1 = Very low priority
7 = Very high priority

Support 1 2 3 4 5 6 7

113 1,5 More support by the social workers while in hospital

Technology

114 6,2 Equipment of the latest technology in quantities (cat scans, magnetic scans, etc)

115 7,4 Equipment of the latest technology and development of nuclear medicine

116 8,3 Hospitals should provide the appropriate equipment and the appropriate specialised staff

117 22,6 Increament of machinery for faster diagnosis (for eg. cat and magnetic scans, cytologic and histologic machinery)

118 26,3 More upto date and better quality scans with high resolution for better diagnosis

Treatment

119 3,1 There should be a possibility for patients with agressive cancer to be treated out of waiting lists

120 3,4 Better management of the treatment's side effects

Extra costs

121 16,1 There should not be a need to give money to doctors in the hospital for better attention

122 16,2 There should n't be a need to give money to nurses in order to help patients with their daily activities (eg. bath, etc)

123 19,4 There should not be a need to give presents to the medical and nursing staff in order to avoid patients' hardship

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2ος ΓΥΡΟΣ

Η Τεχνική 'Δελφοί' στην Έρευνα για τις Ογκολογικές Υπηρεσίες στην Ελλάδα

Πώς να συμπληρώσετε το ερωτηματολόγιο:

Τοποθετείστε το σημείο X στο τετράγωνο που περιγράφει καλύτερα την γνώμη σας σχετικά με προτεραιότητα που θα δίνατε στις προτάσεις που ακολουθούν.

Η κλίμακα κυμαίνεται από "πολύ χαμηλή προτεραιότητα" (1)
"χαμηλή προτεραιότητα" (2)
"μέση χαμηλή προτεραιότητα" (3)
"ούτε χαμηλή ούτε υψηλή προτεραιότητα" (4)
"μέση υψηλή προτεραιότητα" (5)
"υψηλή προτεραιότητα" (6) και
"πολύ υψηλή προτεραιότητα" (7).

Panel no

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

Επικοινωνία

			1	2	3	4	5	6	7
1	3,2	Η ανακοίνωση της διάγνωσης του καρκίνου πρέπει να γίνεται με καλύτερο τρόπο							
2	19,7	Οι γιατροί και οι νοσηλευτές δεν έχουν την κατάλληλη εκπαίδευση για να αντιμετωπίσουν τέτοιες "λεπτές" ασθένειες. Απαιτείται βελτίωση στην επικοινωνία							
3	25,5	Το νοσηλευτικό προσωπικό πολλές φορές δεν γνωρίζει τι ξέρει ο ασθενής για την ασθένειά του, και ενεργούν σαν να μην ξέρουν τι έχει ο ασθενής							
4	29,1	Το νοσηλευτικό προσωπικό πρέπει να ξέρει τους ασθενείς που περιποιούνται, δεν πρέπει να κάνουν τις ίδιες ερωτήσεις στους ασθενείς όλη την ώρα							

Μονάδες ημέρας

5	13,1	Κλινικές ημέρας							
6	18,2	Οι κλινικές ημέρας πρέπει να αναπτυχθούν, τα υπάρχοντα κρεβάτια δεν είναι αρκετά							

Εκπαίδευση/Κατάρτιση

7	9,3	Εκπαιδευμένες νοσηλεύτριες							
8	11,2	Πρόσθετη εκπαίδευση για τις νοσηλεύτριες που χορηγούν χημειοθεραπεία για να μην καταστρέφουν τα χέρια των ασθενών με το τοξικό φάρμακο							
9	19,1	Το νοσηλευτικό προσωπικό στα γενικά νοσοκομεία είναι αδιάφορο και δεν έχουν εκπαιδευτεί για να φροντίζουν τους ασθενείς με καρκίνο							
10	20,2	Το ιατρικό και νοσηλευτικό προσωπικό πρέπει να είναι πολύ ευαίσθητο σχετικά με την έγκαιρη αναγνώριση των ειδικών συμπτωμάτων του καρκίνου							
11	23,1	Το νοσηλευτικό προσωπικό στα γενικά νοσοκομεία δεν φαίνεται να έχει την κατάλληλη εκπαίδευση σχετικά με την ασθένεια. Απαιτείται βελτίωση στην επικοινωνία							
12	24,1	Οι γενικοί γιατροί πρέπει να εκπαιδεύονται κατάλληλα ώστε να μπορούν να αναγνωρίζουν τα πρώτα συμπτώματα του καρκίνου							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
13	25,3 Όλοι οι γιατροί πρέπει να γνωρίζουν τα συμπτώματα καρκίνου, προκειμένου να εντοπίζουν τον καρκίνο νωρίς, στην αρχή του							
14	26,2 Οι ογκολόγοι έχουν υψηλό επίπεδο επιστημονικής κατάρτισης, αλλά χρήματα πρέπει να παρασχεθούν για επιπλέον εκπαίδευση σε ογκολογικά κέντρα στο εξωτερικό							
15	26,5 Το νοσηλευτικό προσωπικό πρέπει να πηγαίνει στο εξωτερικό, τουλάχιστον μία φορά το χρόνο, για επιπλέον εκπαίδευση							
16	27,3 Οι γιατροί και οι νοσηλευτές που εργάζονται στα ειδικά ογκολογικά κέντρα πρέπει να εκπαιδευτούν κατάλληλα							
17	29,4 Οι γιατροί και οι νοσηλευτές πρέπει να είναι προσεκτικότεροι όταν δίνουν τη χημειοθεραπεία γιατί συμβαίνουν πολλά λάθη και τα φάρμακα είναι τοξικά							
	Επιπλέον κρεβάτια							
18	19,3 Δεν πρέπει να αφήνουν τους ασθενείς στους διαδρόμους για ώρες ή ακόμα και ημέρες. Αυτό προκαλεί τη φυσική και ψυχολογική εξουθένωση των ασθενών							
19	25,2 Το Ελληνικό κράτος πρέπει να δώσει περισσότερη προσοχή στον τομέα της υγείας, οι ασθενείς δεν πρέπει να νοσηλεύονται στους διαδρόμους							
	Χρηματοδότηση							
20	6,3 Παροχή φαρμάκων από όλες τις ασφαλιστικές εταιρείες							
21	25,6 Καλύτερη παροχή υπηρεσιών από τις ασφαλιστικές εταιρείες. Μερικές από αυτές προσφέρουν πάρα πολύ λίγα							
	Κατ' οίκον φροντίδα							
22	7,1 Πρέπει να υπάρχει νοσηλεία κατ' οίκον (για τις εξετάσεις αίματος, την θεραπεία, αλλαγές καθετήρων, κ.λ.π.)							
23	21,3 Επέκταση της νοσηλείας κατ' οίκον έτσι ώστε οι ασθενείς να μπορούν να τελειώσουν στο γνωστό περιβάλλον τους, με αξιοπρέπεια και την αγάπη των							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

			1	2	3	4	5	6	7
24	22,3	Οργανωμένη κατ' οίκον νοσηλεία και καλύτερη ποιότητα φροντίδας για τον ασθενή με καρκίνο							
25	23,4	Η φροντίδα κατ' οίκον θα ήταν χρήσιμη για πολλούς ασθενείς ώστε να μην γεμίζουν τα κρεβάτια στο νοσοκομείο							
26	29,3	Η φροντίδα κατ' οίκον πρέπει να αναπτυχθεί, ώστε οι ασθενείς με καρκίνο να μην είναι απαραίτητο να πηγαίνουν στο νοσοκομείο για ασήμαντα πράγματα							
		Μονάδες Τελικής Φροντίδας							
27	6,1	Ειδικοί χώροι για τους αρρώστους τελικού σταδίου, οι οποίοι χρειάζονται ειδική προσοχή							
28	7,2	Θα έπρεπε να υπάρχουν ειδικά μέρη για τους ασθενείς που είναι στο τελικό στάδιο της ασθένειας, οι οποίοι χρειάζονται ειδική φροντίδα							
29	23,2	Η θεραπεία των ασθενών με καρκίνο στο τελικό στάδιο πρέπει να προσφέρεται σε ειδικά ιδρύματα, επειδή στα νοσοκομεία δεν έχουν την ανάλογη προσοχή							
30	30,4	Ειδικά ιδρύματα πρέπει να δημιουργηθούν για τους ασθενείς με καρκίνο στο τελικό στάδιο, ώστε να μην νοσηλεύονται στα νοσοκομεία όπου δεν τους δίνουν καμία προσοχή							
		Περιβάλλον νοσοκομείων							
31	15,2	Τα κτήρια των νοσοκομείων είναι άθλια							
32	29,2	Οι κλινικές ημέρας πρέπει να είναι πιό ευχάριστες							
		Πληροφόρηση							
33	7,3	Εθνικό δίκτυο πληροφόρησης							
34	9,2	Περισσότερες πληροφορίες στους συγγενείς από τους ογκολόγους							
35	10,2	Πληροφορίες από το γιατρό για την ασθένεια							
36	11,4	Ειλικρινής πληροφόρηση από τους γιατρούς, επειδή η γνώση είναι δύναμη							

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			1	2	3	4	5	6	7
37	23,3	Οι κατάλληλες πληροφορίες από όλους μπορεί να αποχαρακτηρίσουν τον καρκίνο από ποινή θανάτου							
38	24,3	Αναλυτικές πληροφορίες στον ασθενή σχετικά με διαθέσιμες θεραπείες και τα αποτελέσματά τους							
39	24,4	Πλήρης πληροφόρηση στους ασθενείς και τους στενούς συγγενείς τους σχετικά με τη διάγνωση, την θεραπεία, τις πιθανές επιπλοκές							
40	25,4	Οι πληροφορίες που παίρνουν οι ασθενείς είναι ανεπαρκείς. Πρέπει να υπάρξουν άλλες υπηρεσίες που θα δίνουν πρόσθετες πληροφορίες στους ασθενείς							
41	26,4	Ο ασθενής πρέπει να ενημερώνεται πλήρως για την εξέλιξη της ασθένειάς του χωρίς ψέματα							
42	27,2	Οι ασθενείς πρέπει να ενημερώνονται πλήρως για την ασθένειά τους και τη κατάσταση της υγείας τους							
43	30,2	Πληροφορίες για την ασθένεια. Η διάγνωση πρέπει να ανακοινώνεται στον ασθενή, και αυτό πρέπει να γίνεται με τον καλύτερο τρόπο							
		Δικτύωση							
44	26,6	Πρέπει να υπάρχει ένα ειδικό μέρος όπου όλοι οι ογκολόγοι να μπορούν να συναντιούνται και να ανταλλάσσουν απόψεις και πληροφορίες							
		Νέες Θεραπείες							
45	26,1	Νέοι τρόποι θεραπείας πρέπει να βρεθούν, αποτελεσματικότερες							
		Οργάνωση							
46	3,3	Δεν υπάρχει καμία οργάνωση στα γενικά νοσοκομεία για τη θεραπεία των ασθενών με καρκίνο, έτσι οι ασθενείς με καρκίνο μεταφέρονται από νοσοκομείο σε νοσοκομείο							
47	4,2	Οργανωμένη παροχή ογκολογικών υπηρεσιών, έτσι ώστε οι ασθενείς με καρκίνο να μην μεταφέρονται από νοσοκομείο σε νοσοκομείο για εξετάσεις και ειδικές θεραπείες							

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		1	2	3	4	5	6	7
48	14,1 Οι εξετάσεις των ασθενών με καρκίνο πρέπει να ολοκληρώνονται στο νοσοκομείο όπου νοσηλεύονται, έτσι ώστε να μην χρειάζεται να μεταφέρονται σε άλλα νοσοκομεία							
49	14,4 Οι εξετάσεις και ειδικότερα οι βιοψίες πρέπει να ολοκληρώνονται γρηγορότερα, δίνοντας προτεραιότητα στους ασθενείς που χρειάζονται θεραπεία γρήγορα							
50	15,1 Υπάρχει έλλειψη συνολικής αντιμετώπισης (εργαστηριακή υποστήριξη) στα νοσοκομεία που παρέχουν ογκολογικές υπηρεσίες							
51	18,4 Στον τομέα των εξετάσεων με ειδικό μηχάνημα ζήτησα ένα ραντεβού τον Ιούλιο και μπορούσαν μόνο τον Δεκέμβριο							
52	21,1 Έγκαιρη διάγνωση. Γρήγορες υπηρεσίες σχετικά με τις εργαστηριακές εξετάσεις (παραδείγματος χάριν οι κυτταρολογικές εξετάσεις παίρνουν πολύ χρόνο)							
53	27,4 Καλύτερη κατανομή των αξονικών τομογράφων και όλου του ειδικού εξοπλισμού και όχι συγκέντρωση στην Αθήνα και Θεσσαλονίκη							
	Αντιμετώπιση του Πόνου							
54	2,1 Καλύτερη αντιμετώπιση του πόνου							
55	19,5 Η διαδικασία χορήγησης ναρκωτικών αναλγητικών στους ασθενείς πρέπει να βελτιωθεί							
56	20,3 Κλινικές πόνου							
57	21,4 Καλύτερη οργάνωση των κλινικών πόνου και όχι μόνο εφαρμογή των patch και τίποτα άλλο							
58	22,5 Οργάνωση και επάνδρωση των κλινικών πόνου με κατάλληλο προσωπικό για βελτίωση της ποιότητα ζωής							
59	24,2 Πρέπει να υπάρχουν κλινικές πόνου σε όλα τα νοσοκομεία για την πλήρη ανακούφιση από τον πόνο							
	Ψυχολογική υποστήριξη							
60	1,3 Μεγάλη έλλειψη ψυχολογικής υποστήριξης κατά τη διάρκεια της θεραπείας							
61	2,2 Ψυχολογική υποστήριξη για τους ασθενείς και τους στενούς συγγενείς							

1 = Πολύ χαμηλή προτεραιότητα
7 = Πολύ υψηλή προτεραιότητα

		1	2	3	4	5	6	7
62	4,1 Πληροφόρηση και ψυχολογική υποστήριξη							
63	8,2 Ψυχολογική υποστήριξη, όχι καλοπιάσματα. Οι ασθενείς με καρκίνο πρέπει να βοηθηθούν να αποδεχτούν το πρόβλημά τους και να μπορέσουν να το διαχειριστούν							
64	10,1 Ψυχολογική υποστήριξη κατά τη διάρκεια της θεραπείας και μετά την έξοδο από το νοσοκομείο							
65	11,1 Πρέπει να προσφέρεται ψυχολογική υποστήριξη και πρέπει να υπάρχουν κοινωνικοί λειτουργοί σε κάθε νοσοκομείο για να δίνουν πληροφορίες στους ασθενείς και στους συγγενείς τους και να τους ενθαρρύνουν							
66	13,3 Ψυχολογική υποστήριξη και μονάδες αποκατάστασης							
67	16,4 Ψυχολογική υποστήριξη πρέπει να προσφέρεται στα μέλη της οικογένειας του ασθενή							
68	19,2 Το νοσηλευτικό προσωπικό στα γενικά νοσοκομεία δεν προσφέρει κανένα είδος ψυχολογικής υποστήριξης ούτε στον ασθενή ούτε στους συγγενείς τους							
69	22,4 Οι μονάδες καρκίνου πρέπει να επανδρωθούν με ψυχολόγο και ψυχίατρο, οι οποίοι σε συνεργασία με τον ογκολόγο θα βοηθήσουν τον ασθενή να αποδεχτεί την ασθένειά του							
70	30,1 Ψυχολογική υποστήριξη από τους γιατρούς και τις νοσηλεύτριες. Πρέπει να διαθέτουν περισσότερο χρόνο στους ασθενείς							
	Δημόσια Υγεία/Προαγωγή Υγείας							
71	10,5 Προληπτικές πληροφορίες μέσω φυλλαδίων, προγραμμάτων ραδιοφώνων και TV, συναντήσεις							
72	11,3 Πρόληψη, που είναι το σημαντικότερο. Πρέπει να ωθήσουν τις γυναίκες με φυλλάδια να εξετάζονται εγκαίρως							
73	16,3 Τα προγράμματα πρόληψης πρέπει να αναπτυχθούν και να βελτιωθούν							
74	20,1 Ο τομέας της πληροφόρησης του κόσμου σχετικά με τις ομάδες υψηλού κινδύνου, τις αιτίες και τα πρόωρα σημάδια του καρκίνου, πρέπει να βελτιωθεί							

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		1	2	3	4	5	6	7
75	21,2 Εκπαίδευση του κόσμου και πληροφορίες σχετικά με την άμεση αναγνώριση των συμπτωμάτων της ασθένειας							
76	22,1 Εκπαίδευση του κοινού και ευαισθητοποίηση για συχνούς ελέγχους στα κατάλληλα κέντρα (όπως τις κλινικές μαστού) από τα μέσα μαζικής ενημέρωσης							
77	22,2 Οργάνωση από διάφορα ιδρύματα (π.χ. εκκλησία, επιτροπές, κ.λπ.) ομιλιών, συναντήσεων για να δίνουν πληροφορίες, προκειμένου να αυξηθούν οι πιθανότητες πρόληψης και να ανιχνευθεί ο καρκίνος νωρίς							
78	28,1 Τα μέσα μαζικής ενημέρωσης πρέπει να συμμετέχουν περισσότερο στον πόλεμο κατά του καρκίνου							

Έρευνα

79	12,2 Καλύτερη έρευνα και προσπάθεια για τη θεραπεία της ασθένειας κάθε ημέρα							
80	28,3 Έρευνα πρέπει να γίνει προκειμένου να βρεθούν καλύτεροι τρόποι να αντιμετωπιστούν οι παρενέργειες της χημειοθεραπείας							

Πόροι

81	1,1 Τα διαγνωστικά εργαστήρια πρέπει να λειτουργούν περισσότερες ώρες έτσι ώστε να είναι μικρότερες οι λίστες αναμονής							
82	1,4 Το νοσηλευτικό προσωπικό πρέπει να αυξηθεί							
83	2,3 Δημιουργία ειδικών μονάδων ή νοσοκομείων για τους άρρωστους τελικού σταδίου							
84	5,1 Ανάπτυξη της περιφέρειας με ειδικευμένο προσωπικό, ιατρικό και νοσηλευτικό, σχετικά με το τον καρκίνο							
85	5,2 Νοσοκομεία πρέπει να χτιστούν στην περιφέρεια, και στα υπάρχοντα να αναπτυχθούν ογκολογικές μονάδες							
86	5,3 Δεν υπάρχουν γιατροί στην περιφέρεια, στις μονάδες ακτινολογίας, οι οποίοι θα διαθέσουν χρόνο για τους ασθενείς με καρκίνο							

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		1	2	3	4	5	6	7
87	8,1 Καταρχήν, πρέπει να υπάρχει αρκετός χώρος, επειδή δεν είναι δίκαιο 16 ασθενείς να είναι στον ίδιο θάλαμο, και είναι καταθλιπτικό για κάποιον στην αρχή της ασθένειας να βλέπει κάποιον στο τελευταίο στάδιο							
88	9,1 Βελτίωση των θαλάμων. Λιγότερα κρεβάτια στους θαλάμους							
89	9,4 Κάθε υπηρεσία σχετικά με τον καρκίνο πρέπει να αναπτυχθεί και αυτές που υπάρχουν πρέπει να βελτιωθούν							
90	27,5 Το Ελληνικό κράτος πρέπει να δείξει περισσότερο ενδιαφέρον για την οργάνωση των ογκολογικών υπηρεσιών							
91	28,4 Τα νοσοκομεία πρέπει να βελτιωθούν							
	Ικανοποίηση							
92	17,1 Οι απόψεις μου σχετικά με το προσωπικό και το χώρο της θεραπείας είναι θετικές							
	Ειδικές Μονάδες Καρκίνου							
93	9,5 Ογκολογικά κέντρα πρέπει να δημιουργηθούν στην περιφέρεια, ώστε να μη χρειάζεται οι ασθενείς να ταξιδεύουν μακριά							
94	10,3 Κατάλληλοι χώροι για την χορήγηση χημειοθεραπείας							
95	10,4 Πρέπει να υπάρχουν οι κατάλληλοι χώροι και οι θάλαμοι στα νοσοκομεία για τους ασθενείς με καρκίνο. Τα νοσοκομεία πρέπει να παρέχουν τα τεχνητά μέλη							
96	13,2 Ογκολογικές μονάδες σε όλα τα νοσοκομεία							
97	23,5 Ογκολογικές μονάδες πρέπει να αναπτυχθούν στην περιφέρεια ώστε να μη χρειάζεται να μεταφέρονται οι ασθενείς χωρίς λόγο							
98	28,2 Ογκολογικές μονάδες πρέπει να δημιουργηθούν στα γενικά νοσοκομεία για τους πιο κοινούς τύπους καρκίνου, με το κατάλληλο προσωπικό							
99	28,5 Ογκολογικές μονάδες πρέπει να χτιστούν στην περιφέρεια ώστε οι ασθενείς με ειδικές ανάγκες να μην χρειάζεται να ταξιδεύουν στην Αθήνα ή στην Θεσσαλονίκη							

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			1	2	3	4	5	6	7
		Συμπεριφορά του Προσωπικού							
100	1,2	Οι γιατροί πρέπει να δίνουν περισσότερη προσοχή και να παρέχουν περισσότερο χρόνο για την εξέταση των ασθενών							
101	3,5	Καλύτερη αντιμετώπιση από το ιατρικό προσωπικό							
102	8,4	Καλύτερη συμπεριφορά από τους γιατρούς και τις νοσηλεύτριες							
103	12,1	Περισσότερη φροντίδα και αγάπη για τους ασθενείς							
104	14,3	Οι νοσηλεύτριες πρέπει να δείχνουν κατανόηση σχετικά με την πιθανή κακή διάθεση των ασθενών με καρκίνο, οι οποίοι, αισθανόμενοι άσχημα για την κατάστασή τους αντιδρούν με παράξενο τρόπο							
105	19,6	Πολλοί γιατροί δεν εμπνέουν αίσθημα εμπιστοσύνης στους ασθενείς και τους συγγενείς τους, έτσι οι ασθενείς προτιμούν να πάνε στο εξωτερικό για καλύτερη διάγνωση και θεραπεία							
		Ελλείψεις Προσωπικού							
106	18,1	Στη μονάδα χημειοθεραπείας που ήμουν το προσωπικό βοηθούσε πολύ, αλλά δεν ήταν αρκετοί							
107	18,3	Το ιατρικό προσωπικό είναι σπουδαίοι επιστήμονες με ευαισθησία και κατανόηση, αλλά δεν είναι αρκετοί, έχοντας ως αποτέλεσμα καθυστερήσεις στα ραντεβού							
108	22,7	Το ειδικευμένο ιατρικό και νοσηλευτικό προσωπικό πρέπει να αυξηθεί							
109	25,1	Το νοσηλευτικό προσωπικό πρέπει να αυξηθεί προκειμένου να προσφέρονται ποιοτικές υπηρεσίες							
110	30,3	Το νοσηλευτικό προσωπικό πρέπει να αυξηθεί και όλα τα κενά πρέπει να καλυφθούν							
		Δεξιότητες προσωπικού							
111	14,2	Οι νοσηλευτές πρέπει να φροντίζουν τους ασθενείς με καρκίνο όπως όλους τους άλλους ασθενείς, κάνοντας τους να αισθάνονται άνετα και να ξεχνούν το πρόβλημά τους							
		Στίγμα							
112	27,1	Δεν πρέπει να υπάρχει το στίγμα του καρκίνου							

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Υποστήριξη

		1	2	3	4	5	6	7
113	1,5 Περισσότερη υποστήριξη από τους κοινωνικούς λειτουργούς κατά τη διάρκεια της νοσηλείας στο νοσοκομείο							

Τεχνολογία

114	6,2 Εξοπλισμός της πιό πρόσφατης τεχνολογίας σε ποσότητες (αξονικοί τομογράφοι, μαγνητικοί τομογράφοι, κλπ.)							
115	7,4 Εξοπλισμός τελευταίας τεχνολογίας και ανάπτυξη της πυρηνικής ιατρικής							
116	8,3 Τα νοσοκομεία πρέπει να παρέχουν τον κατάλληλο εξοπλισμό και το κατάλληλο ειδικευμένο προσωπικό							
117	22,6 Αύξηση των ιατρικών μηχανημάτων για γρηγορότερη διάγνωση (π.χ. αξονικοί τομογράφοι και μαγνητικοί τομογράφοι, κυτταρολογικά και ιστολογικά μηχανήματα)							
118	26,3 Πιο σύγχρονοι και καλύτερης ποιότητας τομογράφοι με υψηλή ανάλυση για καλύτερη διάγνωση							

Θεραπεία

119	3,1 Πρέπει να υπάρχει δυνατότητα για τους ασθενείς με επιθετικό καρκίνο να προηγούνται στις λίστες αναμονής							
120	3,4 Καλύτερη αντιμετώπιση των παρενεργειών από τις θεραπείες							

Πρόσθετες Δαπάνες

121	16,1 Δεν πρέπει να δίνονται χρήματα στους γιατρούς στο νοσοκομείο για καλύτερη προσοχή							
122	16,2 Δεν πρέπει να δίνονται χρήματα στους νοσηλευτές προκειμένου να βοηθούν τους ασθενείς με τις καθημερινές δραστηριότητές (π.χ. λουτρό, κλπ)							
123	19,4 Δεν είναι ανάγκη να δίνονται δώρα στο ιατρικό και νοσηλευτικό προσωπικό προκειμένου να αποφευχθεί η ταλαιπωρία των ασθενών							

Appendix 13

Accompanying letter to the second round questionnaire of health care users' Q-Delphi study

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Athens,

Thank you for replying on the first round of this 'Delphi' study about the cancer services in Greece. One hundred and twenty three suggestions were made by all the participants. A panel analysed all the suggestions and categorised them under themes. On the second round questionnaire, included in the envelope, the suggestions are presented under these themes. I am asking you to rate these suggestions on a scale that ranges from 1 (very low priority) to 7 (very high priority).

I would be grateful if you complete and post back the questionnaire in the pre-paid envelope provided as soon as possible.

Your help for the completion of this study is immense and I would like to thank you again.

N. Efstathiou
RGN, MSc

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Αθήνα,

Σας ευχαριστώ για την απάντηση στον πρώτο γύρο της έρευνας "Δελφοί" για τις ογκολογικές υπηρεσίες στην Ελλάδα. Εκατόν είκοσι τρεις προτάσεις παρήχθησαν από όλους τους συμμετέχοντες. Μια επιτροπή ανέλυσε όλες τις προτάσεις και τις ταξινόμησε κάτω από κατηγορίες. Στο δεύτερο ερωτηματολόγιο, που περιλαμβάνεται στο φάκελο, οι προτάσεις παρουσιάζονται κάτω από αυτές τις κατηγορίες. Σας ζητώ να εκτιμήσετε την προτεραιότητα σε αυτές τις προτάσεις σε μια κλίμακα που κυμαίνεται από 1 (πολύ χαμηλή προτεραιότητα) ως 7 (πολύ υψηλή προτεραιότητα).

Θα ήμουν ευγνώμων εάν συμπληρώνατε και στέλνατε πίσω το ερωτηματολόγιο στον προπληρωμένο φάκελο που σας παρέχεται το συντομότερο δυνατόν.

Η βοήθειά σας για την ολοκλήρωση αυτής της μελέτης είναι απαραίτητη και θα επιθυμούσα να σας ευχαριστήσω πάλι.

Ν. Ευσταθίου
Νοσηλευτής, MSc

A92

Appendix 14

The WHO recommendations for countries of low and high level of resources

Component	All countries	Scenario A: Low level of resources	Scenario B: Medium level of resources	Scenario C: High level of resources
National cancer control programme	• Develop a national cancer control programme to ensure effective, efficient and equitable use of existing resources • Establish a core surveillance mechanism to monitor and evaluate outcomes as well as processes • Develop education and continuous training for health care workers	• Consider the implementation of one or two key priorities in a demonstration area with a stepwise approach • Consider palliative care as an entry point to a more comprehensive approach • Use appropriate technologies that are effective and sustainable in this type of setting	• When initiating or formulating a cancer control programme, consider implementation of a comprehensive approach in a demonstration area using a stepwise methodology • Use appropriate technologies that are effective and sustainable in this type of setting	• Full, nationwide implementation of evidence-based strategies guaranteeing effectiveness, efficiency, and accessibility • Implement a comprehensive surveillance system, tracking all programme components and results • Provide support for less affluent countries
Prevention	• Implement integrated health promotion and prevention strategies for noncommunicable diseases that include legislative/regulatory and environmental measures as well as education for the general public, targeted communities and individuals • Control tobacco use, and address alcohol use, unhealthy diet, physical activity and sexual and reproductive factors • Promote policy to minimize occupational-related cancers and known environmental carcinogens • Promote avoidance of unnecessary exposure to sunlight in high risk populations	• Focus on areas where there are great needs and potential for success • Ensure that priority prevention strategies are targeted to those groups that are influential and can spearhead the process (e.g., policy-makers, and teachers) • In areas endemic for liver cancer, integrate HBV with other vaccination programmes	• Develop integrated clinical preventive services for counselling on risk factors in primary health care settings, schools and workplaces • Develop model community programmes for an integrated approach to prevention of noncommunicable diseases	• Strengthen comprehensive evidence-based health promotion and prevention programmes and ensure nationwide implementation in collaboration with other sectors • Establish routine monitoring of ultraviolet radiation levels if the risk of skin cancer is high
Early diagnosis	• Promote early diagnosis through awareness of early signs and symptoms of detectable and curable tumours that have high prevalence in the community, such as breast and cervical cancer • Ensure proper diagnostic and treatment services are available for the detected cases • Provide education and continuous training to target populations and health care providers	• Use low cost and effective community approaches to promote, in a first phase, early diagnosis of one or two priority detectable tumours in a pilot area with relatively good access to diagnosis and treatment	• Use low cost and effective community approaches to promote early diagnosis of all priority detectable tumours	• Use comprehensive nationwide promotion strategies for early diagnosis of all highly prevalent detectable tumours
Screening	• Implement screening for cancers of the breast and cervix where incidence justifies such action and the necessary resources are available	• If there is already infrastructure for cervical cytology screening, provide high coverage of effective and efficient cytology screening for women aged 35 to 40 years once in their lifetime or, if more resources are available, every 10 years for women aged 30 to 60 years	• Provide national coverage cytology screening for cervical cancer at 5 year intervals to women aged 30 to 60 years	• Effective and efficient national screening for cervical cancer (cytology) of women over 30 years old and breast cancer screening (mammography) of women over 50 years of age
Curative therapy	• Ensure accessibility of effective diagnostic and treatment services • Promote national minimum essential standards for disease staging and treatment • Establish management guidelines for treatment services, essential drugs list, and continuous training • Avoid performing curative therapy when cancer is incurable and patients should be offered palliative care instead	• Organize diagnosis and treatment services giving priority to early detectable tumours	• Organize diagnosis and treatment services, giving priority to early detectable tumours or to those with high potential of curability	• Reinforce the network of comprehensive cancer treatment centres that are active for clinical training and research and give special support to the ones acting as national and international reference centres
Pain relief and palliative care	• Implement comprehensive palliative care that provides pain relief, other symptom control, and psychosocial and spiritual support • Promote national minimum standards for management of pain and palliative care • Ensure availability and accessibility of opioids, especially oral morphine • Provide education and training for carers and public	• Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care in targeted areas and that there is high coverage of patients through services provided mainly by home-based care	• Ensure that minimum standards for pain relief and palliative care are progressively adopted by all levels of care and nationwide there is rising coverage of patients through services provided by primary health care clinics and home-based care	• Ensure that national pain relief and palliative care guidelines are adopted by all levels of care and nationwide there is high coverage of patients through a variety of options, including home-based care

Appendix 15

The consensual statements by healthcare providers

Consensual statements by healthcare providers	Min	Max	Mean	SD
25. Home care should be developed for oncology patients not only during treatment but for terminally ill patients	7	7	7,00	0,00
102. Nurses should be employed by the Greek state in order to overcome the problem of shortage of staff in home care services	6	7	6,95	0,22
50. Greater attention should be given to the management of pain. Health professionals should be informed and educated in pain management. Pain clinics	5	7	6,86	0,47
23. Services like home care should be developed for terminally ill cancer patients, for better quality of life at the last stages of life	6	7	6,86	0,35
41. Day units should be increased in Oncology hospitals in order to serve more cancer patients (day units, out patients' radiotherapy), so that patients stay more at their home environment	5	7	6,86	0,47
14. Screening services in hospitals should be operating more hours, so that waiting lists get shorter (waiting period for a mammography may take 4 months)	4	7	6,83	0,65
103. The number of nursing staff should be increased in Oncology hospitals	6	7	6,82	0,39
64. Psychological support should be provided to cancer patients and their families through all the stages of the disease	5	7	6,78	0,52
81. The system connecting the Health Centres with the hospitals should be improved	5	7	6,77	0,61
53. Pain management services should be developed by pain clinics, offering pain management not only during treatment but when at home, through all the stages of the disease	5	7	6,77	0,53
86. Insurance companies should cover cancer patients during all the phases of the disease (diagnosis-treatment-rehabilitation)	4	7	6,77	0,69
123. Working coditions must be improved so that working in a hospital becomes less stressful	6	7	6,77	0,43
92. Education (basic-post-continuing) must be improved for all health professionals (doctors-nurses-psychologists-social workers)	4	7	6,74	0,75
79. All health professionals who come in contact with cancer patients should get special training in communication skills (how to tell the diagnosis, bad news regarding treatment, etc)	5	7	6,74	0,54
91. Educational centres must be developed to provide an oncology nursing specialty	4	7	6,74	0,75
33. Home care services should be provided by all oncology centres	6	7	6,73	0,46
24. Services like home care should be provided by doctors, nurses and social workers	6	7	6,73	0,46

	Min	Max	Mean	SD
62. Psychological support should be given by professionals not only on diagnosis but during treatment too	5	7	6,70	0,63
94. Doctors and nurses must receive communication improvement courses	5	7	6,70	0,56
90. Doctors and nurses in oncology hospitals should be specialised in offering personalised care to cancer patients eg. Pain assessment, vomiting, quality of life	5	7	6,70	0,63
89. Emphasis should be given in staff's education who work in special oncology hospitals	5	7	6,70	0,63
63. Psychological support groups must be created in oncology hospitals, consisting of psychiatrist, nurses, psychologist and social workers	5	7	6,68	0,65
109. A registration program of all the cancers on national level must be developed	4	7	6,68	0,72
71. Psychological support for nurses working in Oncology wards. Support groups must be created by nurses for nurses in conjuction with counsellors	5	7	6,65	0,71
69. Psychological support groups must be created for the support of patients and families not only in the hospital but in the community too	5	7	6,61	0,66
18. Cancer hospitals should be built in the greater area of Greece so that cancer patients won't have to travel far for special treatment	4	7	6,61	0,84
101. The big shortage of specialised nursing staff requires the immediate elaboration and application of a total plan for the engagement and staying of nurses in the profession	4	7	6,55	0,86
104. Oncology wards should be staffed with social worker and psychologist	4	7	6,50	0,86
8. Prevention programs against cancer should be developed	4	7	6,48	0,85
95. Doctors and nurses should be properly educated to recognise cancer symptoms at an early stage and diagnosis should be made as soon as possible	5	7	6,45	0,74
49. Development of palliative care for the patients either at home or in special hospitals and institutions	4	7	6,45	0,80
3. Cancer prevention programs should be developed with the co-operation of all health professionals	4	7	6,43	0,73
39. Health Centres should employ nurses so that home care services may be provided to the community around the Health Centres	4	7	6,43	1,12
40. Day units should be developed as well as special intensive care units, physiotherapy units and home care services in all oncology hospitals	4	7	6,41	0,96
87. Wiser financial arrangements should be made so money will not be wasted. Money should be spent wisely foe equipment and machinery that is necessary for the treatment of cancer patients	4	7	6,41	0,80

	Min	Max	Mean	SD
56. Oncology hospitals must become independent, functional, efficient, non-beraucratic, noninstitution look like environment. The environment of oncology hospitals must not bring in mind an impersonal institution	4	7	6,39	0,94
99. All health professionals should attend seminars on communication skills	4	7	6,35	0,98
2. Media should provide information to people on cancer prevention	4	7	6,26	1,05
127. There should be a possibility for young cancer patients to continue their education at the hospital	4	7	6,00	1,27

Συναινετικές προτάσεις από τους επαγγελματίες υγείας	Min	Max	Mean	SD
25. Η κατ' οίκον νοσηλεία πρέπει να αναπτυχθεί για τους ασθενείς με καρκίνο όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και για τους ασθενείς τελικού σταδίου	7	7	7,00	0,00
102. Πρέπει να προσληφθούν νοσηλευτές από το κράτος ώστε να υπερνικηθεί το πρόβλημα της έλλειψης του προσωπικού στις υπηρεσίες κατ' οίκον	6	7	6,95	0,22
50. Μεγάλη προσοχή πρέπει να δοθεί στην αντιμετώπιση του πόνου. Οι επαγγελματίες υγείας πρέπει να ενημερώνονται και να εκπαιδεύονται στην αντιμετώπιση του πόνου. Κλινικές πόνου	5	7	6,86	0,47
23. Υπηρεσίες σαν την κατ' οίκον νοσηλεία πρέπει να αναπτυχθούν για τους αρρώστους τελικού σταδίου με καρκίνο, για καλύτερη ποιότητα ζωής στα τελευταία στάδια της ζωής	6	7	6,86	0,35
41. Μονάδες ημερήσιας νοσηλείας πρέπει να αναπτυχθούν καθώς επίσης και ειδικές μονάδες εντατικής παρακολούθησης, μονάδες φυσιοθεραπείας και υπηρεσίες κατ' οίκον νοσηλείας σε όλα τα νοσοκομεία ογκολογίας	5	7	6,86	0,47
14. Οι υπηρεσίες προληπτικού ελέγχου στα νοσοκομεία πρέπει να λειτουργούν περισσότερες ώρες, έτσι ώστε οι λίστες αναμονής να είναι μικρότερες (η περίοδος αναμονής για μια μαστογραφία μπορεί να πάρει 4 μήνες)	4	7	6,83	0,65
103. Ο αριθμός του νοσηλευτικού προσωπικού πρέπει να αυξηθεί στα ογκολογικά νοσοκομεία	6	7	6,82	0,39
64. Ψυχολογική υποστήριξη πρέπει να παρέχεται στους ασθενείς με καρκίνο και τις οικογένειές τους σε όλα τα στάδια της ασθένειας	5	7	6,78	0,52
81. Το σύστημα που συνδέει τα Κέντρα Υγείας με τα νοσοκομεία πρέπει να βελτιωθεί	5	7	6,77	0,61
53. Αντιμετώπιση του πόνου από τις κλινικές πόνου, προσφέροντας αντιμετώπιση του πόνου όχι μόνο κατά τη διάρκεια της θεραπείας αλλά και στο σπίτι, σε όλα τα στάδια της ασθένειας	5	7	6,77	0,53
86. Οι ασφαλιστικές εταιρείες πρέπει να καλύπτουν τους ασθενείς με καρκίνο κατά τη διάρκεια όλων των φάσεων της ασθένειας (διάγνωση-θεραπεία-αποκατάσταση)	4	7	6,77	0,69
123. Οι συνθήκες εργασίας πρέπει να βελτιωθούν έτσι ώστε το στρες να είναι λιγότερο	6	7	6,77	0,43
92. Η εκπαίδευση (βασική-μεταβασική-συνεχόμενη) πρέπει να βελτιωθεί για όλους τους επαγγελματίες υγείας (γιατρούς-νοσηλευτές-ψυχολόγους-κοινωνικούς λειτουργούς)	4	7	6,74	0,75
79. Όλοι οι επαγγελματίες υγείας που έρχονται σε επαφή με ογκολογικούς ασθενείς πρέπει να λάβουν ειδική εκπαίδευση στην επικοινωνία (πώς να ανακοινώνεται η διάγνωση, δυσάρεστες ειδήσεις σχετικά με τη θεραπεία, κ.λπ...)	5	7	6,74	0,54
91. Εκπαιδευτικά κέντρα πρέπει να αναπτυχθούν για να παρέχουν την ειδικότητα ογκολογικής νοσηλευτικής	4	7	6,74	0,75
33. Η κατ' οίκον νοσηλεία πρέπει να παρέχεται από όλα τα ογκολογικά νοσοκομεία στην Ελλάδα	6	7	6,73	0,46
24. Υπηρεσίες όπως η κατ' οίκον νοσηλεία πρέπει να προσφέρονται από τους γιατρούς, τις νοσηλεύτριες και τους κοινωνικούς λειτουργούς	6	7	6,73	0,46

	Min	Max	Mean	SD
62. Ψυχολογική υποστήριξη πρέπει να παρέχεται από τους επαγγελματίες όχι μόνο κατά τη διάγνωση αλλά και κατά τη διάρκεια της θεραπείας	5	7	6,70	0,63
94. Οι γιατροί και οι νοσηλευτές πρέπει να παρακολουθήσουν σειρές μαθημάτων βελτίωσης της επικοινωνίας	5	7	6,70	0,56
90. Οι γιατροί και οι νοσηλευτές στα ογκολογικά νοσοκομεία πρέπει να είναι ειδικευμένοι στην προσφορά εξατομικευμένης φροντίδας στους ασθενείς με καρκίνο π.χ.. Αξιολόγηση του πόνου, έμεση, ποιότητα ζωής	5	7	6,70	0,63
89. Έμφαση πρέπει να δοθεί στην εκπαίδευση του προσωπικού που εργάζεται στα ειδικά ογκολογικά νοσοκομεία	5	7	6,70	0,63
63. Ομάδες ψυχολογικής υποστήριξης πρέπει να δημιουργηθούν στα ογκολογικά νοσοκομεία, και να αποτελούνται από ψυχίατρο, νοσηλεύτριες, ψυχολόγο και κοινωνικούς λειτουργούς	5	7	6,68	0,65
109. Ένα πρόγραμμα καταγραφής όλων των καρκίνων σε εθνικό επίπεδο πρέπει να αναπτυχθεί	4	7	6,68	0,72
71. Ψυχολογική υποστήριξη για τους νοσηλευτές που εργάζονται σε ογκολογικές μονάδες. Οι ομάδες υποστήριξης πρέπει να δημιουργηθούν από τους νοσηλευτές για τους νοσηλευτές σε συνεργασία με ειδικούς συμβούλους	5	7	6,65	0,71
69. Ομάδες ψυχολογικής υποστήριξης πρέπει να δημιουργηθούν για την υποστήριξη των ασθενών και των οικογενειών τους όχι μόνο στο νοσοκομείο αλλά και στην κοινότητα	5	7	6,61	0,66
18. Ογκολογικά νοσοκομεία πρέπει να χτιστούν στη ευρύτερη περιοχή της Ελλάδας έτσι ώστε οι ασθενείς με καρκίνο να μην χρειάζεται να ταξιδεύουν μακριά για ειδικές θεραπείες	4	7	6,61	0,84
101. Η μεγάλη έλλειψη ειδικευμένου νοσηλευτικού προσωπικού απαιτεί την άμεση επεξεργασία και την εφαρμογή ενός συνολικού σχεδίου για τη προσέλκυση και την παραμονή των νοσηλευτών στο επάγγελμα	4	7	6,55	0,86
104. Οι ογκολογικές κλινικές πρέπει να επανδρωθούν με κοινωνικούς λειτουργούς και ψυχολόγους	4	7	6,50	0,86
8. Πρέπει να αναπτυχθούν προγράμματα πρόληψης κατά του καρκίνου	4	7	6,48	0,85
95. Οι γιατροί και οι νοσηλεύτριες πρέπει να εκπαιδευτούν κατάλληλα για να αναγνωρίζουν τα συμπτώματα του καρκίνου σε ένα αρχικό στάδιο και η διάγνωση να γίνεται το συντομότερο δυνατόν	5	7	6,45	0,74
49. Ανάπτυξη της παρηγορητικής φροντίδας για τους ασθενείς είτε στο σπίτι είτε στα ειδικά νοσοκομεία και τα ιδρύματα	4	7	6,45	0,80
3. Πρέπει να αναπτυχθούν προγράμματα πρόληψης του καρκίνου με τη συνεργασία όλων των επαγγελματιών υγείας	4	7	6,43	0,73
39. Τα Κέντρα Υγείας πρέπει να προσλάβουν νοσηλεύτριες ώστε οι υπηρεσίες κατ' οίκον νοσηλείας να μπορούν να παρασχεθούν στην κοινότητα γύρω από τα Κέντρα Υγείας	4	7	6,43	1,12
40. Μονάδες ημερήσιας νοσηλείας πρέπει να αναπτυχθούν καθώς επίσης και ειδικές μονάδες εντατικής παρακολούθησης, μονάδες φυσιοθεραπείας και υπηρεσίες κατ' οίκον νοσηλείας σε όλα τα ογκολογικά νοσοκομεία	4	7	6,41	0,96

	Min	Max	Mean	SD
87. Προσεκτικές οικονομικές ρυθμίσεις πρέπει να γίνουν ώστε να μην σπαταλούνται χρήματα. Τα χρήματα πρέπει να ξοδεύονται σοφά για εξοπλισμό και μηχανήματα που είναι απαραίτητα για τη θεραπεία των ασθενών με καρκίνο	4	7	6,41	0,80
56. Τα ογκολογικά νοσοκομεία πρέπει να είναι ανεξάρτητα, λειτουργικά, αποδοτικά, μη- γραφειοκρατικά, χωρίς το περιβάλλον να θυμίζει ίδρυμα.. Το περιβάλλον των ογκολογικών νοσοκομείων δεν πρέπει να φέρνει στο μυαλό ένα απρόσωπο ίδρυμα	4	7	6,39	0,94
99. Όλοι οι επαγγελματίες υγείας πρέπει να παρακολουθήσουν σεμινάρια επικοινωνίας	4	7	6,35	0,98
2. Τα media πρέπει να παρέχουν πληροφορίες στον κόσμο για την πρόληψη του καρκίνου	4	7	6,26	1,05
127. Πρέπει να υπάρχει η δυνατότητα για τους νέους ασθενείς με καρκίνο να συνεχίσουν την εκπαίδευσή τους στο νοσοκομείο	4	7	6,00	1,27